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VETERANS' ADMINISTRATION SPINAL CORD INJURY PROGRAM

HEARING

BEFORE THE

SUBCOMMITTEE ON HOSPITALS AND HEALTH CARE

OF THE

COMMITTEE ON VETERANS' AFFAIRS HOUSE OF REPRESENTATIVES

NINETY-SEVENTH CONGRESS

SECOND SESSION

JULY 28, 1982

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VETERANS' ADMINISTRATION'S SPINAL CORD INJURY PROGRAM

WEDNESDAY, JULY 28, 1982

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HOSPITALS AND HEALTH CARE,
COMMITTEE ON VETERANS' AFFAIRS,
Washington, D.C.

The subcommittee met, pursuant to call, at 9 a.m., in room 334, Cannon House Office Building, Hon. Ronald M. Mottl (chairman of the subcommittee) presiding.

Present: Representatives Mottl, Applegate, Boner, Mica, Daschle, Dorgan, Hillis, McEwen, Dunn, and Smith of Alabama.

OPENING STATEMENT OF CHAIRMAN MOTTL

Mr. MOTTL. Good morning. The subcommittee will come to order.

This morning we are meeting to receive testimony on the Veterans' Administration's spinal cord injury program. We expect to cover all aspects of the SCI program, including the number of SCI centers, the staffing of such centers, any difficulties in recruiting and retaining personnel to provide quality care to SCI veterans, the current medical research activities in this area, and the funding available to support this research.

In the past, the Veterans' Administration has been the recognized leader in the treatment and rehabilitation of the spinal cord injured. The VA's work with SCI veterans has been incorporated into the vast improvement of the care of all the people of this Nation and the entire world.

However, we are fearful that the VA's leadership role has diminished in the past few years, and we are concerned that the funding requirements for the maintenance of the best facilities, the recruitment and retention of top-flight personnel, and an ongoing research effort has slipped to the point that we may no longer be able to say that the VA SCI centers are the leaders in the care of these patients. For the VA to be in a lesser role is totally unacceptable, and I am anxious to learn from the witnesses what the present situation is and what steps are being taken to again place the VA in the position of being the best in the business.

During this subcommittee's hearing on the VA 5-year medical facilities construction plan on March 11, 1981, we received testimony that in early 1980 the VA had 1,365 SCI beds. At that time the VA estimated that by fiscal year 1985, 1,845 beds at a minimum would be needed in the SCI program. We are anxious to learn if this figure still holds and what progress has been made to meet

this requirement now that we are at the midpoint of this 6-year projection.

We would also like to know what percentage of SCI veterans would be able to receive treatment at any one time based upon the number of beds available and how many SCI veterans are presently on the waiting list for the beds available at this time.

A sufficient number of properly located SCI centers is essential if SCI veterans are to receive timely care. Because of this fact, we are concerned with testimony we also received in that March 11, 1981, hearing—that there are no SCI centers located between the Mississippi River and the Pacific coast. We anticipate that the VA will advise us if there are any plans for such a center. At the time of the hearing, there was some discussion that Salt Lake City, Utah, would be a centralized location for a new center, and we would like an update on this matter.

Another issue of primary importance to the members of the subcommittee and the SCI veterans is the area of regeneration research. We expect to learn of the VA's developments in this area and if any funding problems are preventing the VA from taking a leading role in advancing such research.

Before I recognize our first witness from the Paralyzed Veterans of America, I would like to recognize one of our dear friends and the acting ranking minority member of the subcommittee, Bud Hillis, the gentleman from Indiana, for his opening remarks.

STATEMENT OF HON. ELWOOD HILLIS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF INDIANA

Mr. HILLIS. I thank the chairman of the subcommittee for recognizing me this morning. I, too, am very happy to have an opportunity to be here and attend these important hearings.

The treatment of spinal cord injuries or diseases by the Veterans' Administration has long been of great interest to this subcommittee. It has not been too many years ago that patients with this type of injury were usually considered as beyond the scope of successful treatment, but the VA, by its concentration on and development of spinal cord injury units has done much to lead the way to at least some success in the treatment and rehabilitation from these catastrophic types of disability.

Our subcommittee knows that with VA leadership medical science has come some distance in this field. Mr. Chairman, it is a gross understatement to say that we have a long way to go. Today we want to be updated in every way possible on what the VA is doing with respect to the treatment of spinal cord disabilities. We want to know about research and what has been accomplished or may be accomplished. We want to know of problems the VA may have and where our committee can be of assistance.

Mr. Chairman, I think it is fair to say that in carrying out our oversight responsibility we want to demonstrate our vital and continuing interest with respect to diseases and injuries of the spinal cord. I look forward to hearing from our witnesses.

Thank you very much.

Mr. MOTTL. Thank you very much, Mr. Hillis.

Mr. MOTTL. Our first witness this morning will be Mr. Jack Powell, executive director of the Paralyzed Veterans of America. Mr. Powell, we welcome you and would like to take this opportunity to commend your organization for its efforts in the development of the spinal cord injury centers. Yours is an outstanding organization and you are an outstanding executive director. We appreciate the expertise that you bring to this hearing.

Before you proceed, I would also like to recognize Mr. Dunn for his activities in this area. I think he has done a fine job.

Also I would like to have a special recognition for a gentleman I met out at Denver, Colo., who is considered by many of the people in this area to be the leader. Dr. Perkash, I would like to welcome you this morning to our hearing. You have done a great job with the SCI center at Palo Alto and you are considered to be, if not the best, one of the best in the world. Just keep up the good work out there. We look forward to your testimony later this morning.

So, Mr. Powell, your entire statement will be submitted into the record without objection, and you may proceed as you deem fit.[1]

STATEMENT OF R. JACK POWELL, EXECUTIVE DIRECTOR, PARALYZED VETERANS OF AMERICA, ACCOMPANIED BY LYNN PHILIPS, RESEARCH DIRECTOR; AND VICTOR McCOY, NATIONAL SERVICE DIRECTOR, PARALYZED VETERANS OF AMERICA

Mr. POWELL. Thank you, Mr. Chairman. It is always a pleasure to appear in front of you and in front of the members of this committee.

Recognizing the statement will be submitted in the record, I will attempt to paraphrase some of the thoughts that are contained in our lengthier written testimony.

As I said, it is indeed a pleasure to be here at this hearing testifying on such a worthy subject, spinal cord injury. As you may have noted from our prepared remarks, it is just this matter that thousands of America's most profoundly disabled veterans have been battling now for some 36-plus years.

As you know, Mr. Chairman, Americans are proud of their heritage, pleased with their traditions, and committed to progress, just so are the members of the Paralyzed Veterans of America. We are proud of the hundreds of young American veterans of virtually every major campaign of World War II who, having already proved their courage, did so once again when they set out to battle with an injury that condemned them to a life expectancy of a mere 6 to 18 months, and in so doing they gave birth to the Paralyzed Veterans of America.

We also, Mr. Chairman, are pleased with the traditions established by that handful and its followers, for from them have come not only the Veterans' Administration's 19 spinal cord injury centers and, following in these tracks, the Department of Health and Human Services trauma centers, but today for all paraplegics and quadraplegics a life expectancy of only 3 to 5 years less than that enjoyed by most other Americans.

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[1] The prepared statement of Mr. Powell appears on p. 41.

Last but not least, we also are committed to progress, a progress with but two simple yet optimistic goals—first, that the best possible health care services be made available to spinal cord injured persons, whether they are veterans or civilians, and second, that through a successful research program for a cure to spinal cord injury there may one day be no more such hearings as these.

It is with America, whose problems seemed daunting in their scope, that the concerns of those interested in spinal cord injuries seem under attack from every side, whether from the reality of diminished resources or the great need of our legitimate interests. Therefore, it is with recognition of these realities, and yet a desire to be simultaneously prudent and compassionate, that our comments are offered.

During the past year PVA has participated with the VA in two monumental undertakings. The first was the establishment of a patient treatment registry for spinal cord injured veterans throughout the VA's 172 hospitals, covering the years from 1976 to the present. Second, PVA screened from the VA's compensation and pension files some 100,000 severely disabled veterans, seeking who among those were spinal cord injured and certain basic information on their collective history. It is from this gold mine of newly available facts, and based on our many years of experience, that we base our statements.

It is certainly true that the VA possess thousands of concerned, dedicated and capable employees. Yet while paying them their due respect, it is unfortunate that I must say that the most common feeling in dealing with the VA is one of profound frustration. The process of transferring even the most simple and clearly needed decision into a reality makes a Gordian knot seem simple.

For example, while the VA debated whether or not to purchase land for the expansion of the Tampa Bay VA Medical Center, a hospital with one of the highest occupancy rates in the system, one of their options expired leaving them without parking facilities for both patients and staff if, in fact, they ever did decide to expand.

The continued bickering over eligibility for health care, both now and in the future, leaves even the most able planners, wherever they might be found, running from pillar to post. And if they have problems, imagine the difficulties faced by the catastrophically disabled veterans in the areas of Palo Alto, Calif., or Houston, Tex., SCI centers, which function at a 93-percent or higher occupancy, who do not know from one day to the next whether or not they can get in for regularly scheduled medical checkups, yet must make complex plans, often in vain, to do so. Once again, we see frustration.

In another regard, the continuous frustration of hospital directors, VA physicians, and veteran patients alike over the availability of beneficiary travel funds, if addressed in a creative manner, could be significantly reduced. PVA proposes the shared use by VA outpatient treatment programs of appropriate Department of Defense facilities and, where indicated, the transportation of specialty medical teams to areas of large densities of veterans rather than the transportation of the veterans to the hospital. For example, if we take the Jacksonville, Fla. area, this area, while short in VA resources, contains both a large number of spinal cord injured vet-

erans and significant Department of Defense health facilities. If, instead of transporting at Government expense several hundred veterans great distances to either the Miami or Tampa SCI units for checkups and other outpatient treatment, the VA were to bring in periodically a team of appropriately trained medical personnel, we might simultaneously assure quality of care and reduce expense.

Similarly, areas like the Rocky Mountain corridor, which you mentioned in your opening remarks, Mr. Chairman, many miles distant from the nearest VA SCI center, yet with numbers of SCI patients, might best and most economically be served by the establishment of spinal cord injury outpatient treatment clinics, leaving the costly transportation of veterans to distant SCI centers for only inpatient treatment.

Quality of care has always been important to PVA, and one way to check on this has been the patient-to-staff ratio. However, a review of the May 31, 1982 report of spinal cord injury centers lists almost 22 percent of the 2,200 authorized FTE under the category of "other," from which, to say the least, it is difficult to ascertain their impact on the quality of care. Here, again, we see repeated frustration.

Much has been said before the members of this committee and others in the past about the impending tidal wave of aging veterans soon to sweep down upon the VA system. PVA, too, is concerned with this looming problem. Never before has the VA or any other health care system been confronted with the problems of caring for large numbers of aged spinal cord injured persons, simply because in the past they have never lived this long.

Knowing well, as do you, how long it takes to build new facilities, PVA has been raising the issue of long-term care for spinal cord injured veterans for several years with an admirable persistency, but a notable lack of results. One example of this situation has arisen at Hines VA Hospital in Chicago, Ill. It is an excellent example of the VA's poor planning which is adversely affecting the health care of some of the most disabled spinal cord injured veterans.

Hines Hospital has a 160-bed acute care SCI facility and a 40-bed long-term care facility that has been recommended for co-location. Planning for this facility is based on the population of spinal cord injured veterans in the Hines-Kechipan area who are in need of long-term care.

Yet a dichotomy exists within the structure of the VA, where the Chief Medical Director bases construction needs and time tables on the assessment of existing and future patient requirements, but the Office of Construction bases construction needs and time tables on existing and projected budget considerations. Here, then, is a problem when health care needs are not met with adequate funding.

But the situation at Hines exceeds this unfortunate reality. Hines represents perhaps the most notable and more urgent example of the VA's failure to provide for the needs of spinal cord injured veterans even when money has been appropriated. Health care experts within the VA have recognized the need for this project. The VA's Department of Medicine and Surgery has seen the need for a long-term care SCI facility at Hines and continues to list one in the VA's 5-year construction plan. The Chief Medical Direc-

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tor has consulted with PVA for over 2 years concerning feasible alternatives to the construction of the needed 40-bed facility.

To bridge the gap which exists between urgent current demands in the construction of a suitable facility, despite this 2-year effort, no adequate solution, either interim or permanent, has been reached by the VA, largely because no alternative to specialized, long-term care will meet the needs of SCI veterans.

There is obvious conflict here between the medical needs of veterans as recognized by the Department of Medicine and Surgery and their ability to produce a solution for the recognized need. The conflict is compounded furthermore because of other forces. It appears that long-term care SCI facilities are some of the most troublesome health care services, simply because aging SCI veterans present hospital administrators and health care personnel with the problems of aging compounded by the complexities associated with spinal cord injury.

At Hines the most recently proposed solution to the absence of a needed long-term care facility is to contract with nursing homes for the care of SCI veterans. Others would be spread throughout the VA nursing home. Still others would be placed in the existing acute-care SCI facility. Last year 18 such veterans were sent by Hines to non-VA nursing homes and this year already 12 have been placed in similar nursing homes.

While the numbers of veterans affected may seem insignificant, and the problems inherent in sending SCI veterans to nonspecialized facilities may not be readily apparent, PVA recognizes several problems in the Hines proposal. First, there is a statutory prohibition against contracting for more than 6 months in cases of nonservice connected disabled veterans. This means the individual SCI veteran will be transferred to a nursing home, then back to the VA long enough to renew his eligibility for contract care, and then out again to another nursing home. It is quite likely that by the time he is eligible for return to a non-VA nursing home, the original nursing home will be filled. The veteran must then go to a different facility.

Second, PVA and many of the VA's own SCI physicians remain fearful of nursing home care for SCI veterans because of the results we have witnessed. Too many SCI veterans are returned for hospitalization after episodes in nonspecialized nursing homes. Care of SCI patients in general nursing homes as often as not ends in a worsening of the individual patient's condition, for a number of reasons. This deterioration creates a need for expensive medical treatment and causes needless suffering for the veteran.

Nonspecialized nursing homes do not have qualified, experienced personnel and they are unable to care adequately for the needs of SCI veterans. Health care statistics support PVA's observation that nonspecialized personnel are not able to recognize symptoms of decubitus ulcers, urinary tract infections, and other ailments common to SCI patients.

PVA has been told that SCI veterans at Hines will be sent only to "accessible" nursing homes. This doesn't comfort us. Having a building that is accessible is not a substitute for personnel who are trained to deal with SCI patients.

Another example of the frustrations encountered in long-term care may be seen with the Brockton Spinal Cord Injury Unit. This unit, located in Massachusetts, consists of 58 beds all dedicated to long-term care and has long had waiting lists for New England area SCI veterans. In the VA's multiyear SCI plan, 22 additional beds were to be constructed here, bringing the total to 80 long-term care beds. PVA, concurring with the report from the VA's Inspector General that 20 beds at the nearby West Roxbury SCI unit were historically underutilized, and recognizing the greater availability of services at West Roxbury, recommended that instead of new construction at Brockton, that beds be converted at West Roxbury. In our opinion both a better quality of services would be available for fragile patients and dollars could be saved for the already strained construction budget.

Now along came the Facilities Planning Service from D.M. & S. and the Office of Construction in the VA, who proposed health and safety construction projects to the Brockton SCI unit, which according to their reports could reduce the number of beds at Brockton by another 35 percent. The progression of events that occurred from that point on are reminiscent merely of the twilight zone. Suffice it to say that at this moment in time the 22 beds recognized as needed in this area are not being built at Brockton, nor are they available at West Roxbury, and in addition, as many as 20 more beds already at Brockton are planned to disappear, hopefully without the patients that presently are in them. Oh, yes, the waiting list at Brockton still exists.

Mr. Chairman, we recognize that part of this hearing concerns itself appropriately with spinal cord injury research, and as I mentioned earlier, research is certainly a priority of PVA's. Because research is covered in our written testimony, and in view of the eminently more capable witnesses to follow me on this subject, I would touch on just one often overlooked, certainly valuable benefit of VA research. Simply put, it is that among the best, brightest and most dedicated physicians in the VA are those who come to the system only because of the opportunity to conduct research. These doctors are capable of earning far more practicing in the private sector. Yet, in return for a relatively handful of dollars and the time for research, their talents are available to veterans and their efforts directly have done much to improve the quality of care available in the VA.

I have personally and directly seen the effect of reductions in VA research funding. During the week of one recent series of cuts, I was visiting a VA hospital where five very talented physicians, upon learning of the cuts, immediately ended negotiations to come to work for the VA.

While those who come after me will eloquently address the direct benefits of adequate research funding—and PVA certainly supports them—I urge you not to overlook these indirect benefits.

Thank you, Mr. Chairman, for indulging our statement, and we will try to answer any questions you have at this time, sir.

[The statement of Mr. Powell appears at p. 41.]

Mr. MOTTL. Thank you, Mr. Powell, for your excellent statement this morning and for your excellent work on behalf of the SCI centers and also the Paralyzed Veterans of America.

I would respectfully request that you introduce for the record your colleagues at the witness table.

Mr. POWELL. Certainly. I overlooked that and I'm sorry.

On my left is PVA's research director, Ms. Lynn Philips, and on my right is PVA's national service director, Mr. Vic McCoy.

Mr. MOTTL. Welcome, also.

The Chair will invoke the 5-minute rule for questioning so we can get around and so that everybody will have an equal opportunity to proffer questions this morning.

First of all, Mr. Powell, why in your opinion would the SCI centers at Palo Alto and Milwaukee and Long Island be considered the best and what do they have there that the other centers seem to lack or need?

Mr. POWELL. I think I can answer that in two ways. One is that there is an impression among the varying incestuous group of people that are called spinal cord injured veterans that the best quality of care exists there because the most concerned physicans are located there, because the programs are comprehensive. It is something that I think is not peculiar simply to the spinal cord injury unit alone that makes that impression, but the cooperation between the spinal cord injury unit, its staff, the other hospital staff, the teaching staff of affiliated hospitals. They all go together.

Mr. MOTTL. Where would you rank the SCI center in Cleveland and what is needed there for improvement so they can reach the caliber of those that I already mentioned?

Mr. POWELL. With due respect to the chairman's home district, we have been trying to figure out where to rank Wade Park for a long time. In November of 1981, PVA and its representatives had a meeting with the chief medical director and many representatives of the department of medicine and surgery. One of the subjects that came up having to do with Wade Park and several other facilities was the question of determining how, in fact, one could be satisfied that the VA SCI centers were capable of delivering the various levels of care that have now been established, whether that be acute care, sustaining care, or long-term care.

It was agreed to by those present that some method of certification needed to be developed. We found shortly after that meeting with the chief medical director that the method to use for certification was the SERP process, which you have probably heard of before. I think many of us have heard of it but I don't think any of us have ever seen it. It seems to be a kind of system wherein I go in and check on Fred and Fred comes over and checks on me and we both write up a report and nobody but Fred or I ever see the report, but we go out and tell someone else that this is a pretty good way to do things.

I think that we will have problems, sir, in trying to rank any of the SCI centers by other than hearsay or word of mouth until we can have—whether it be this committee or some other committee of Congress, or any outside source—have some kind of access to what we are supposed to believe is the effective system for assuring quality of care in VA hospitals, which is not shared, to the best of my knowledge, with anyone outside of the VA system today.

Mr. MOTTL. Thank you.

Has there been any improvement there at Cleveland?

Mr. POWELL. There seems to have been some willingness to do something there, which is always the first step, to get some momentum going. We are optimistic. The problems there are myriad. They are not peculiar to that center. The Bronx VA Hospital, which is a most new and most eminently well-funded VA hospital, it is beautiful and it's gleaming and it is chrome and it's brand new and it has the best of equipment and everything else. It has many, many problems, too. So those who would like to say the problems with Wade Park are simply because of location or because they have antiquation certainly aren't doing anything to resolve the problem. It is more basic than the facilities.

Mr. MOTTL. My last question, Mr. Powell. Do you foresee the need for additional SCI centers and an increase in SCI bed numbers?

Mr. POWELL. There can be no question about the additional need, Mr. Chairman, especially and most importantly in the long-term care area, which as I pointed out earlier, has been a very frustrating area for us to deal in.

When this organization began, paralyzed people did not live. That is why we began. Six to eighteen months was not a life expectancy; it was a sentence. Today spinal cord injured people live 3 to 5 years shorter than a normal life expectancy. Since the majority of spinal cord injuries occur between 16 and 25 years of age, we are talking about 40 to 50 years in a wheelchair. That means many of them get old today that never got old before. Many of them have spouses who get old today that never got old before and who no longer are capable of providing the attendant care in a home-base situation that the veteran needs to exist outside. That means he is going to come back to the VA system for health care. Yet we have seen no positive strides taken toward resolving the long-term care needs of this highly dependent and highly deserving group of people.

If we could ask for any one thing out of this hearing, Mr. Chairman, we would ask that this subcommittee decide to require the VA to report back to it within some reasonable period of time its plan for resolving the long-term care needs of catastrophically disabled spinal-cord-injured veterans.

Mr. MOTTL. I think that is a reasonable request. We should make that request to the VA.

The gentleman from Michigan, who as I stated before has done a lot in this area and he is to be commended, do you have any questions of Mr. Powell at this time, Mr. Dunn?

Mr. DUNN. I thank the chairman.

Let me also take the opportunity to say that the chairman and I sat down and talked last year about holding hearings on this and I appreciate your willingness and your interest and support.

I have two questions really for Mr. Powell. We talk about resources in the VA or without the VA committed to regeneration research. Can you tell me a little bit about PVA's abilities and amount of funding in this area that you are committed to on regeneration research?

Mr. POWELL. I would like to let Lynn Philips, our research director, answer that, sir.

Ms. PHILIPS. Thank you. I appreciate having the opportunity to talk about our research program.

At the present time PVA has a technology and research foundation, which has been in existence for a little over 6 years, and in that period of 6 years we have given over $2 million in research funds to various areas having to do with spinal cord injuries, and approximately $1.2 million of that has gone into regeneration research.

The other areas that we have given funding in pertain to applied medical care and technological advances, improved wheelchairs, and so forth.

Mr. DUNN. The second question—and you touched on it before—is in the area of communications. On regeneration research, it seemed to be the consensus of—and you say it in your testimony—of the medical community, that very little, up until maybe 1970, was believed was ever possible to accomplish. Nevertheless, today I think there is a different attitude. You are spending research dollars; the VA is spending research dollars; independent research agencies are also. But I detect that there is very little communication between these various organizations, in talking about the various research and how to better coordinate it.

In 1980 we had the office set up out in Oregon, and yet I think very little has happened out there. President Carter set up a task force to study it. I believe that task force met exactly twice.

So I guess my question to you would be twofold. No. 1, do you think communication between either private hospitals or groups such as yourself and the VA is what it should be, and if not, how could we really better communicate without setting up another task force? How can we really accomplish that?

Mr. POWELL. Sir, I——

Mr. DUNN. I know there is no easy answer to that question.

Mr. POWELL. I note that Mr. Carter's committee, as you pointed out, died a very untimely death, in very early infancy.

Interestingly enough, I just came yesterday evening from Minneapolis, Minn., where the National Spinal Cord Injury Association was holding their annual convention with one of the other principal consumer groups involved in supporting spinal cord injury research and exactly this same subject came up.

We have never been before so close to the real probability of the fact there may be in a very short period of time, with an adequate amount of funding, no future people like PVA to come and take up the members of this committee's time. You address correctly one very important aspect to insure that that happens, and that is how do we stimulate communication.

The VA, as you pointed out, has its Office of Regeneration Research in Portland, Oreg. I have to admit personally to being embarrassed to have only found out about its existence some 6 months ago, and still have never been able to understand how it came to be at Portland, Oreg. One of the things that amazes me is we have a regeneration research facility at Portland, Oreg., and there is no SCI facility there that the VA has. Yet that is where it has its regeneration research facility. It is building an SCI center in Seattle, and it just built another one down in Palo Alto, Calif.

We recently held a clinic of respiratory care for high-level quadriplegics. We hold it in an area in Alabama that has no VA SCI center. There isn't one in the entire State of Alabama. If the VA is leading in a field, then why isn't the VA showing that it's leading by holding some of these things at its own facilities instead of going somewhere else that has none of these VA facilities to do these kinds of things? It comes right back home to research.

If we got together with the people, both in the VA system and former products of the VA system who are conducting SCI research, and sat down and communicated on where we're at, and how do you put the parts together—because there is some belief that there is the real potential to do that—I think we might be advanced.

One thing that we could say is within the resources of the VA, to require the VA simply to look at and take some positive step on improving the communications between spinal cord injury researchers in the United States. Certainly the VA has taken the lead in health care and it should take the lead in research.

Mr. DUNN. Let me just clarify what you say there.

We are saying that we have a VA that set up an Office of Regeneration Research in Portland, Oreg., in 1980, essentially to communicate, and that you and the PVA, the most interested group in the country, 2 years later haven't heard anything from them?

Mr. POWELL. I may just be the 10 percent that never gets the word, sir.

Mr. DUNN. I sincerely doubt that's the case.

Thank you.

Mr. MOTTL. Thank you very much, Mr. Dunn.

The gentleman from South Dakota, Mr. Daschle. Do you have any questions of the witness?

Mr. DASCHLE. Thank you, Mr. Chairman. I do not have any questions at this time, but I appreciate the testimony.

Mr. MOTTL. Thank you very much, Mr. Daschle.

The gentleman from Alabama, Mr. Smith, do you have any questions of Mr. Powell?

Mr. ALBERT LEE SMITH. Mr. Powell, to carry on further on Congressman Dunn's questions, my district is Birmingham, Ala., where we have a VA center. I know we have a fine Spain Rehabilitation Center which is doing spinal cord injury treatment there in the area at the University of Alabama Medical Center. Of course, the VA Medical Center works with the University of Alabama Medical Center, and yet Birmingham is not designated as one of the SCI centers for the VA.

From how many different sources is the Federal Government providing funding for SCI centers around the United States, and how many SCI centers are there under these various funding programs?

Mr. POWELL. To the best of my knowledge, sir, there are only two directly, and that is the VA spinal cord injury centers and those facilities that come under HHS, the trauma treatment. I believe there are approximately 13 of those now.

Certainly, in trying to track down how all the Government dollars go through research and the dollars that go through medicare and medicaid, which are used in large part for the payments of

people that come into these facilities, I don't know that we could ever identify all the different dollars, where they come from and where they go.

I must point out, sir, that when I made my statement before about conducting a high-level quad respiratory care thing in Alabama, the point was the VA conducted it—the VA has 19 SCI centers. Doesn't it have one that knows enough about high-level respiratory care for quadraplegics to be able to conduct it at one of its own? Does it have to go outside of its own system to do it, to one that it doesn't even recognize?

Now, something must be wrong. Either they are not good enough in the VA system, or they ought to be recognizing Spain.

Mr. SMITH. The question of trying to coordinate and avoid duplication and to communicate seems to me to be very important in order to maximize the effectiveness of the money that is being spent in research and treatment in this area.

Another question that I have: What percentage of those being treated by the VA—and maybe I need to ask Dr. Brown this—are service connected? Would you have any idea of those treated by the VA that are service-connected spinal cord injuries?

Mr. POWELL. We can check it very quickly, sir, if you would bear with us for a moment.

According to the best of my memory, though, while we're looking at it, it is somewhere between 20 and 40 percent actually in the SCI center. Treated by all VA facilities, it is something like 60 percent that are service connected.

Mr. SMITH. Sixty percent are service connected for spinal——

Mr. POWELL [continuing]. Treated by all VA facilities.

You talk about coordinating things, sir. In 1971 the Chief Medical Director of the VA, with an ad hoc advisory committee on spinal cord injury, said we need a registry of spinal cord injured patients. We need that to know where they're at, to know how many there are, to know how to spend the dollars to provide some kind of health care. Until 1981, not one iota of effort ever took place on the establishment of that registry. Finally now one has become available. How many millions of dollars have we spent, perhaps inappropriately, in the intervening 10 years? Finally now, in a year's period of time, significant steps could be taken to create one, 10 years later after it was noted that we needed it.

Mr. SMITH. You indicated that there are 19 VA SCI centers, and then 13 that HHS has?

Mr. POWELL. Approximately 13. I could be off on that. I don't know where they're at but the budget cuts back and forth.

Mr. SMITH. So there are a total of 32 around the country. Based on that census, are they strategically located do you think, where the concentration of people with the spinal cord injuries are located?

Mr. POWELL. I think we need to take some different evaluations. Spinal cord injury care is broken into three types of care: acute, sustaining, and long term. I am probably not using the right words for the doctors, but that is basically the way I have come to understand it in 12 years.

Acute care occurs everywhere there are people, primarily between the ages of 16 and 25, but without respect to race, without

respect to education, without respect to income, without respect to activity. So acute care centers have to be placed simply on the basis of where people are congregated at.

Sustaining care facilities we need to see a significant increase of, in the warm Sun Belt climate areas, if you want to call them that, because every piece of evidence that we have seen over the course of the last 10 years—and our most recent studies show this is where the spinal cord injured confined to a wheelchair is increasingly moving. They are moving there to get out of the cold weather of Michigan, or my home in Illinois, and unfortunately sometimes even northern Ohio. They are moving there to enjoy a better opportunity to participate in life. This is where we need to increasingly look at both sustaining care and long-term care.

Mr. MOTTL. The gentleman from Florida, Mr. Mica.

Mr. MICA. Mr. Chairman, I don't have a question. I would just like to say that I commend you for holding these hearings. I think it is important that we lay the needs on the public record and also just to express my own concern.

In these periods of budget cutting, we seem to look at places that maybe we shouldn't be looking, to make changes in our budget, and I hope the Veterans' Administration as well as the National Institutes of Health will consider the need for basic research. I found in politics that basic research is a subject of great demagoguery, but the importance of basic research in our Federal budget and in our Veterans' Administration budget cannot be overstated. That is where we are going to find some solutions.

I hope as the Veterans' Administration officials sit through these hearings they understand that many of these problems will take continued dedication to basic research as well as meeting the current and everyday needs.

Thank you, Mr. Chairman.

Mr. MOTTL. Thank you, Mr. Mica. I would agree with that commentary.

The gentleman from North Dakota, Mr. Dorgan.

Mr. DORGAN. Thank you, Mr. Chairman.

First of all, I apologize for being late, but we have a markup going on in the Agriculture Committee right at the moment.

I did want to indicate my interest and I am going to take Mr. Powell's statement and the other statements back with me.

Mr. Chairman, I think that these hearings are very important and very productive. I am sure the entire subcommittee will be benefited by the kind of information we will receive from these testimonies. Thank you very much.

Mr. MOTTL. Thank you very much, Mr. Dorgan.

Mr. Powell, do you believe the staffing levels of health care professionals in the SCI centers is adequate to provide quality health services to the spinal cord injured, and what sort of advice would you give the committee to assist the VA in recruiting and retaining the health care professionals needed, particularly nurses, to expand and improve the program?

Mr. POWELL. I have never understood the staffing level, because Lynn Philips from my staff conducted a survey a couple of years back in which she tried to find out what do physical therapists do, what do corrective therapists do, what do occupational therapists

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do, and everyone else simply on spinal cord patients. Every one of them, depending on what facility you go to, the physical therapist may do any one of a different number of things. Her same duties at another facility may be done by a corrective therapist; in another facility they may be done by a nursing assistant. It makes it extremely difficult to try to determine what is an appropriate staff-to-patient ratio because you don't know what the component parts are going to be responsible for at any given facility.

I have become increasingly convinced of late that in the VA's new proposed nursing homes, whether they be for SCI patients or not, that staffing levels there are not adequate to provide care for the most severely in need of care, the aging veteran, again whether they are spinal cord injured or not. The staffing ratios anticipated for the new VA nursing homes are principally to take care of self-care patients, those who will be least likely, if there are indeed changes in eligibility, to ever get into the nursing home in the first place to get care.

The things that I think can be done are some creativity, which is almost dissynonymous with the VA, insofar as the use and flexibility of nurses and other nondegree nursing personnel. Many of the things that are being done by private sector hospitals with some success to lure, recruit, and train nurses have not even been tried in the VA system. Little things that seem almost silly to us sitting here that have been used in hospitals across the country, such as travel groups that go together and organize trips for some of the nursing staff at reduced prices, and for their families and this kind of thing when they go on vacation. It doesn't take much to do it. It doesn't really take any money. It just takes somebody with a little time to do that kind of thing, and a little coddling or fostering of getting it started, that seed fertilized, by the VA system in the first place.

The problem in recruiting physical therapists to make up the rehabilitation programs of the VA has been virtually incredible. It has taken anywhere from 6 to 12 weeks to get them recruited through the Office of Personnel Management. No newly graduated physical therapist can afford to sit and wait for 1½ to 3 months before they can go to work to start earning a paycheck. And once they are hired, they are hired anywhere from $3,000 to $5,000 less than what they would get if they went to work in the private sector. So how can the VA then compete and run a rehabilitation program? The VA has not itself been able to fill, on a permanent basis, the Assistant Chief Medical Director slot for rehabilitation for an extended period of time, and yet while it hasn't been able to do that, we have had problems at the VA research facility in New York, we have had problems with prosthetics around the country, we have had problems with recruiting physical therapists to run rehabilitation programs, all of these programs coming directly under the ASMD for Rehabilitation Services who hasn't been filled. If we can't get one in Washington, how are we ever going to get enough around the country?

Mr. MOTTL. An excellent answer.

You have done a great job and we really appreciate your being here this morning, Mr. Powell, and we will look for your counsel and advice on how to improve this program because it is extremely

important and is probably one of the backbones of the entire program for hospital health care for our veterans.

Thank you for an excellent job this morning.

Mr. POWELL. Thank you, sir.

Mr. MOTTL. The next panel we will hear from is Dr. D. Earl Brown, Jr., Associate Deputy Chief Medical Director, and also Dr. Juan Fonseca, Director, spinal cord injury program, Veterans Administration.

Without objection, your entire statement will be submitted into the record,[1] Dr. Brown and Dr. Fonseca, and for the record, if you would introduce your colleagues before you commence.

We want to welcome you here this morning and we look forward to your statements.

STATEMENTS OF D. EARL BROWN, JR., M.D., ASSOCIATE DEPUTY CHIEF MEDICAL DIRECTOR, AND JUAN FONSECA, M.D., DIRECTOR, SPINAL CORD INJURY SERVICE, ACCOMPANIED BY HOLLIS BOREN, M.D., ASSISTANT CHIEF MEDICAL DIRECTOR FOR RESEARCH AND DEVELOPMENT; GARY J. KRUMP, ACTING DEPUTY ASSISTANT GENERAL COUNSEL; AND MELINDA C. HENDERSON, RNP, MSN, FAAN, CHIEF, NURSING PRACTICE/GERONTOLOGY AND LONG TERM CARE, AND CHIEF, NURSING PROGRAMS, REGION IV, ALL OF THE VETERANS' ADMINISTRATION

STATEMENT OF DR. BROWN

Dr. BROWN. I would like to introduce those I brought from central office. On my right is Dr. Hollis Boren, who is the ACMD for Research and Development. On his right is Mr. Gary Krump from the General Counsel's Office. On my left is Dr. Juan Fonseca, the head of the Spinal Cord Injury Service; and on his left is Miss Mindy Henderson from Nursing Service.

Mr. Chairman and members of the subcommittee, I am pleased to have the opportunity to discuss the Veterans' Administration's spinal cord injury program. The VA has played a pioneer role in the management of the spinal cord injured since World War II.

Spinal cord injury is a disability primarily afflicting young men. It is a disability which almost invariably had an early fatal outcome until 1945. At the end of World War II that coincided with the discovery of sulfonamides and the antibiotics. This changed the life expectancy of the spinal cord injured dramatically so that most of the 2,000 American combat casualties from World War II survived that injury.

The Veterans' Administration assumed the care and treatment of the spinal-cord-injured patients whom military hospitals had gathered in special centers. Thus began a unique medical specialty which the agency has continued, building that service until it now manages 19 spinal cord injury centers.

In its beginning, the VA treatment program established some large centers, namely, at Long Beach, Hines in Chicago, Memphis, West Roxbury, Bronx, and Richmond. With the gradual increase in the patient population and the broad geographic distribution of SCI

[1] The prepared statement of Dr. Brown appears on p. 51.

veterans, the VA has expanded this service by creating additional, smaller units, now totaling 19, as I said, with more than 1,300 total SCI beds.

Spinal cord injury causes a catastrophic disability with an incidence nationwide of 3 per 100,000 in the general population. There are estimated to be 150,000 spinal cord injured individuals in the United States, approximately 20,000 of which are veterans.

Whereas the veteran population coming to the VA for their health care needs amounts to about 10 percent of the Nation's veterans, 75 percent of the veterans who are spinal cord injured use the VA for their health care needs. This is due to the availability of special skills at the VA centers, no less than to the expensive nature of this catastrophic disability.

Prolonged hospitalization and a variety of recurring complications can contribute to make this disability an unusually expensive one. These patients are prone to serious, incapacitating complications, such as urinary infections, pressure sores and pneumonia, all of which require repeated hospitalizations, sometimes for long periods of time. Though vastly improved, the life expectancy of the spinal cord injured still depends upon the severity of the injury. Of course, the more severe the injury, the shorter the life expectancy.

In a recent study covering program experience between 1976 and 1981, we found that the VA medical centers treat more than 16,000 individual spinal-cord-injured veterans. This number includes approximately 900 new patients per year and nearly half of these represent new injuries which require intensive rehabilitation.

The VA SCI centers provide a full range of medical and rehabilitation services managed by a multidisciplinary team of professionals, headed by a physician, and including registered nurses, social workers, psychologists, physical medicine and rehabilitation therapists and so forth.

The initial handling of the newly spinal cord injured individual at the accident site is of paramount importance with respect to such factors as mobilization, preservation of the airway, and control of shock. Fortunately, this special handling has improved dramatically in this country with the training of paramedical personnel and with the dissemination of basic information on first aid and cardiopulmonary resuscitation to the general public. This has resulted in preservation of life and improved function for the SCI victim.

The VA's SCI program goal of rehabilitation is to return the SCI veteran to the mainstream of society, with the attitudes, skills, assistive devices and equipment necessary to function as independently as possible in the physical, social, and vocational areas. The expected outcome of treatment of a new injury is that after medical stabilization, the patient will be able to complete a program of comprehensive and intensive rehabilitation in a period of 4 to 6 months post-injury. Most SCI veterans achieve a successful therapeutic rehabilitation. Eighty-five percent of the SCI discharges are to the patient's own home. Approximately 6 percent of the SCI patients are discharged to a nursing home program, either within the VA or in the community, and the remaining patients go to community hospitals or rehabilitation centers.

The VA program which we feel makes the greatest contribution to the successful care of the SCI veteran in the community is SCI home care. Whenever possible, an SCI patient is placed in this program following initial discharge. Under home care, the patient and family are supervised and directed on the patient's care and treatment until they can manage without assistance. Sixteen of our VA SCI centers now have home care teams.

A considerable amount of the SCI veterans' medical care is being furnished by VA medical centers which do not have SCI centers. The social work service in VA medical centers without SCI centers screen all SCI patients applying for inpatient and outpatient care to provide appropriate counseling, referral services, and informational materials, to insure that all SCI veterans receive appropriate care.

Mr. Chairman, research on spinal cord injury and regeneration receives a high priority because of the severity of the disability, its long-term duration, and the life support systems required by patients with spinal cord injury. As a high priority area, projects which are of high scientific quality receive full funding. In fiscal year 1981, the VA funded 168 such projects for a total of $2.5 million.

The VA research programs address a wide array of problems. They are the urgent problems of the acute spinal cord injury which are being investigated to determine how to limit the functional loss resulting from spinal cord injury and to prevent the sequence of events leading to further damage which may become irreversible. They are the practical everyday problems requiring solution to improve the quality of life of the spinal cord injured patient.

Another area which offers the most future promise, which has already been alluded to in this session, is research directed to stimulate the orderly regrowth or regeneration of nerves in the area of spinal cord damage. VA research programs to improve the quality of life of spinal cord injured patients are an integral part of the overall rehabilitation program.

By applying the best technology improvement can be realized in five areas. Systems are developed to assist the handicapped in the activities of daily living, such as eating, shaving, answering the telephone, reading a book, et cetera. To improve the mobility of patients, much effort has gone into the search for a better wheelchair and into problems of prevention and cure of pressure sores. The development of manipulative devices and their control systems offer the handicapped the possibility of gainful employment. To avoid a life of isolation and confinement, travel with automotive adaptive equipment and enhanced recreational devices have been developed. During fiscal year 1981, funding for 19 such research projects was $1.1 million.

In order to develop targeted programs and to attract talented investigators to regeneration research, the VA had a planning workshop on March the 7, 1980, and the result of that has already been alluded to, the establishment of an Office of Regeneration Research at the VA medical center in Portland, Oreg., under the direction of Frederick J. Seil, M.D. The function of this office is the promotion of quality research in tissue regeneration. The goals include development of a central file to monitor progress of regeneration re-

search within the VA and to correlate VA research with those outside the VA, to facilitate communication among VA scientists involved in regeneration research, to promote training in regeneration research, and to work with representatives of other funding agencies to develop joint funding for combined proposals.

The VA is committed to continuing the provisions of high quality medical care and rehabilitation to the spinal cord injured veteran. In support of this mission, we continue to encourage and fund as a high VA priority research on spinal cord injury and regeneration.

Mr. Chairman, that concludes my statement. I will be pleased to respond to any questions.

[The statement of Dr. Brown appears on p. 51.]

Mr. MOTTL. Thank you very much, Dr. Brown, for your fine statement. We will proffer some questions at this time, if you don't mind.

First of all, I would like to be a little parochial and ask about Cleveland, if I may. Why isn't Cleveland's SCI unit the same caliber as out in Palo Alto or Milwaukee or Long Island?

Dr. BROWN. Certainly Cleveland has had its problems, and I think a part of that problem has been a lack of consistent leadership. I think we have made some progress there, and I would like to ask Dr. Fonseca if he would address the details of that.

Dr. FONSECA. The situation at Cleveland I think to a large extent is a matter of personal perceptions, and also reputation. The director or chief of the service at Cleveland is a man of national reputation in the field of research, research on spinal cord injury, the mechanics of spinal cord injury. He is a highly qualified orthopedist and a very competent individual. Unfortunately, he is only part time, and because he is part time, and because some of that part time is devoted to research, which is done right at the hospital, he probably has not devoted as much time to becoming visible to the patient population and to the organizational structure of the service.

I visited Cleveland in the fall and I became cognizant of the situation which I had some suspicion about before. I tried to make some changes and talked to him extensively, and that is what I believe accounts for the improvement that has been occurring. Part of the improvement is the fact that we have given him additional personnel. He now has two more physicians than he had 2 years ago, and also we gave him additional personnel for home care types of activity.

Cleveland actually is an excellent setting. It is an excellent university that it is affiliated with, and the chief of the service has a university appointment and he is highly respected. I think Cleveland has a future.

Cleveland also had an underutilization problem, and we have officially reduced their beds from 80 to 60. So, like Mr. Powell, I am optimistic about the future of Cleveland.

Mr. MOTTL. So you would perceive, Dr. Fonseca, that Cleveland has the potential to become an SCI center of the same potential of Palo Alto, Milwaukee and Long Island under the present leadership?

Dr. FONSECA. I think it has potential for being an excellent center, yes.

Mr. MOTTL. Does it have the potential of being the best?

Dr. FONSECA. That's a very conjectural type of question. I do not know, sir. It depends on what the future holds.

Mr. MOTTL. Pardon?

Dr. FONSECA. It depends on what the future holds in the way of events and so on.

Mr. MOTTL. What we will do, we have a roll call on at this point. Mr. Boner of Tennessee will assume the chair when we come back, and we will resume the questioning with Mr. Dunn of Michigan, if you will be kind enough just to remain with us and then we'll have some more questions for both of you.

Dr. BROWN. Thank you, Mr. Chairman.

Mr. MOTTL. We will recess for about 10 minutes.

[Whereupon, the subcommittee was in recess.]

Mr. BONER [presiding]. OK. We will now reconvene.

Before I proceed with questions that I might have, Representative Dunn, do you have some questions you would like to ask?

Mr. DUNN. Thank you, Mr. Chairman.

Dr. Brown, mostly I would like to talk about the spinal cord research program at the VA. You correctly called the research done there being one of your priority items. How many priority items are in that research? I understand there are four or five a year that the VA targets.

Dr. BROWN. I will pass that to Dr. Boren.

Dr. BOREN. The VA's high priority research areas are, Congressman, agent orange, aging, alcoholism, delayed stress, spinal cord injury—and schizophrenia.

Mr. DUNN. So we're basically talking about three priority areas right now.

Do you envision over the next couple of years spinal cord research staying as one of those priorities?

Dr. BOREN. Yes, sir, I certainly do.

Mr. DUNN. Looking at the word priority, how do you define priority? Can you define priority for me?

Dr. BOREN. We use the word in two ways, Congressman. It is used in our merit review boards to refer to a numerical rate given for scientific relevance. That is not what we mean when we say priority in a budgetary item. We mean that these meet the missions of the agency and, therefore, will be considered to be given full funding, because we are unable to give full funding for most of our projects. So when we use that term in the broadest sense, we mean full funding of those projects that have passed merit review.

Mr. DUNN. In looking at the total research budget, you have a figure of $128 million medical, and part of that is prosthetic research. Medical research, I believe the figure for 1982 is $118,406,000. When it comes to spinal cord research, again your testimony, you use the number $2.5 million. That calculates out to 2 percent of that research budget. That seems to be a discrepancy, between that and the word priority.

Dr. BOREN. All of the projects that we have had submitted were funded. These were all of the submissions that passed scientific merit. We would hope that with the submission of additional proposals that these would also have been funded. But this is a small amount of money and we agree with this.

As the projects come in and funding is available in future years, we certainly do look forward to that increasing, Congressman.

Dr. BROWN. I might add that because this is a high priority item we are seeking additional submissions for research, and they will be given high priority along with the rest. As Dr. Boren said, we funded all with merit and we are willing to fund more.

Mr. DUNN. Your other two priority items, can you tell me how much of the budget they get of the $128 million, or $118 million?

Dr. BOREN. Could we supply that for the record?

Mr. DUNN. You don't have it there?

Dr. BOREN. I didn't bring it with me.

[Subsequently, the Veterans' Administration furnished the following information:]

It is important to understand what VA Research and Development means by "high priority." The majority of medical research done in the VA is investigator-initiated. That is, clinician-investigators conduct studies dealing with health care problems encountered in their daily treatment of veterans. This research deals with most health problems that affect veterans. In addition, the VA reviews data on prevalent disease entities affecting veterans to identify those areas where a concentrated research effort might prove especially productive. The high priority program provides funds to specifically address those areas in a focused way. This is in addition to the research being conducted under the usual investigator-initiated research. The following is a breakdown of fiscal year 1982 support to the high priority areas:

Spinal cord injury regeneration	$2,344,623
GRECC (aging)	1,750,874
Alcoholism	1,112,725
Agent orange	479,472
Delayed stress disorders of Vietnam veterans	419,856
Schizophrenia	346,266

Mr. DUNN. I agree with what you say about looking towards the future, and yet this has been a priority item in both your testimony for 1981 and 1982, and yet I have some misgivings about when you say it will continue to be a priority and you will continue to increase it, because for those two years it has amounted to that 2 percent figure.

I just frankly can't make a relationship between 2 percent and the word priority. Something's amiss somewhere. I'm not sure what it is.

The only answer you're giving me is you will take a look at it for 1983?

Dr. BOREN. The answer is that if we get the additional projects that come in, and if there are funds, we will fund them.

Mr. DUNN. Can you give me an idea on the dollar amount?

Dr. BROWN. No, not until we get the submissions, the requests for funding.

Mr. DUNN. Can you explain to me how the merit review panel works, Dr. Boren, how you decide on these grant requests?

Dr. BOREN. Surely. The request comes from the individual investigator in one of our hospitals, who prepares the standard protocol with all the justifications, aims and methods, relevance and so on. This request goes through the hospital's research and development committee. If human subjects are involved, as many are in our hospitals, it goes through the human subjects subcommittee. If animals are involved, it goes through the laboratory animal subcommittee. If that local research and development committee approves

the project and its scientific merit, the director of the hospital will sign off and forward it for central office review.

In central office we have some 14 merit review boards that then look at these projects for their scientific merit and for their relevance and assign a priority scoring—another use of the word priority. If it is sufficiently high—we do not fund anything between 34 to 50—then funding will be recommended. This has been a partial funding except for the higher priority areas. There's the big difference in what is meant by priority area.

Those funds are then sent back to the hospital to be administered for the research to be done there.

Mr. DUNN. One final question.

We were talking to Mr. Powell earlier about this area of communications. The VA does have a center in Portland, Oreg.—and he is not the only PVA member to make me aware of that. My brother is a surgeon in Dallas and is working in research and he has had no communication, either.

How much Government money has gone to that research center in Portland, and if they haven't communicated with a group the size of PVA, who have they communicated with and how much of the taxpayer's money have we spent in not communicating?

Dr. BOREN. That office is supported at the level of $55,000 a year. They just started back in 1980. They had their first gathering in 1981. They prepared their proceedings and submitted it for publication to the Journal of Science. Science said it no longer accepted that type of proposal. We now have another proposal that will go forward that we will be glad to give you a copy of. The first newsletter is going to hit the streets now. It is in process and will continue.

In addition to that, they have sent other newsletters quarterly to everyone concerned, and I am as distressed as you are that the PVA has not gotten a copy.

Mr. DUNN. You're saying for $55,000 we have gotten one newsletter and one article?

Dr. BOREN. No, $55,000 a year to support the Office of Regeneration Research in the Portland hospital. There have been multiple newsletters.

[Subsequently, the Veterans Administration furnished the following information:]

The Office of Regeneration Research was established at the Portland VAMC in fiscal year 1981 after national competition. The purpose of the office was to communicate with VA scientists regarding regeneration research in order to stimulate studies in this area. The area of research being addressed by this office is the basic biological processes associated with nerve and limb regeneration. Studies in these areas will hopefully provide practical results 5-15 years in the future.

Since it began operation in late fiscal year 1981, the Portland office has screened all VA research in the area of nerve regeneration; had daily contact with VA researchers interested in this area; conducted one conference/workshop with both VA and non-VA participation; written a Regeneration Newsletter; and is going to hold a symposium in September 1982, further emphasizing and discussing research in nerve regeneration. The support in terms of funding to the Portland office has been minimal, in fiscal year 1981—$5,289; in fiscal year 1982—$45,714; and projected for fiscal year 1983—$51,051. The office is scheduled for evaluation in fiscal year 1983.

Mr. DUNN. What can we do besides that?

Dr. BOREN. Well, this is one of the things that——

Mr. DUNN. We have got the PVA; we have got private research going on; we have got other agencies in the Government. I am concerned about overlapping and duplication and wasting the taxpayers money.

This research center doesn't seem to be the answer. Is there a better answer?

Dr. BOREN. It comes back to our coordinating the Federal activities with the National Institute of Neurology, Community Disorders and Stroke. They put some $15 million a year into regeneration research, out of a $265 million budget, or 6 percent of their budget goes into regeneration research.

Now, we have members of the professional staff that sit on that council. We have the same investigators. In the past there was an interagency coordinating committee, which is no longer active, to look at the overlapping and coordination of their endeavors.

It is a major function of the office of regeneration to try to get correlation and stimulate interest and develop investigators in this important area.

Mr. DUNN. Should the NINCDS, because of that number, take the lead, or should the lead be taken by the VA?

Dr. BOREN. I think the VA should, Congressman.

Mr. DUNN. We would agree they aren't?

Dr. BOREN. Yes, sir, agree very much.

Mr. DUNN. Thank you.

Mr. BONER. Dr. Brown, according to page 11 of your testimony, during 1981 the VA had 1,337 operating spinal cord injury beds, or a 5-year average of 1,365 SCI beds. Representative Mottl noted in his opening remarks that this same average existed in 1980, but that the VA had estimated that by fiscal year 1985, 1,845 beds at a minimum would be needed to sustain the SCI program.

Has the VA's position on the number of beds needed changed, or are you planning to increase the number of beds?

Dr. BROWN. That initial projection was simply a projection based upon the best information that was available at that time. We have better information now. The registry that Mr. Powell referred to, wherein we have been collecting data for a little over a year now, will give us a much better feel for not only how many beds there should be, but where they should be geographically. That is what we are using to develop our new plan for spinal cord injury beds.

As of today, we don't know exactly how many we need for that time. We are projecting somewhere around 1,500 beds.

Mr. BONER. So you have reduced your projection then by about 300 or so?

Dr. BROWN. That's right.

Mr. BONER. In February 1980, the VA's Department of Medicine and Surgery published its spinal cord injury program plan for fiscal years 1980–87, which was a broad analysis of the VA's SCI program to include staffing needs, medical specialties required, and other appropriate health care matters.

Are there plans to use the report to plan for long-term care, a proper mix of acute care, sustaining care and long-term care SCI beds, in treatment plans for aging SCI veterans which is a relatively new field?

Dr. BROWN. Yes, sir, we are including that in our plans in several different ways. Not only is the registry going to help us to identify exactly how many there are and where they are, and therefore help us to plan our long-term beds, we also have efforts going on in central office such as the geriatrics steering committee which we have set up to look at the aging veterans with all types of difficulty, and that, too, will add to our planning as far as the long-term care of the aging veteran.

Mr. BONER. I would like to defer to Mr. Ralph Casteel who has a question to ask.

Mr. CASTEEL. Dr. Brown, I have one question to follow up on one Mr. Dunn asked. On page 14 of your testimony you indicated in fiscal year 1981 the VA funded 168 projects in spinal cord injury—this is research projects—for a total of $2.5 million. Now, my calculator tells me that is less than $15,000 per project.

What do you expect to accomplish by that amount of money going into each spinal cord injury project?

Dr. BROWN. Mr. Casteel, first of all, each project that was approved was fully funded for the amount that they asked for, and they requested the amount in order to complete whatever their project was. I realize that doesn't sound like much——

Mr. CASTEEL. In other words, you are saying that on an average each of these research projects only asked for less than $15,000?

Dr. BOREN. I believe that is an incorrect figure. In looking at the backup material on this, it shows there were 55 projects for the $2 million, instead of 168.

Mr. CASTEEL. Well, 168 is in the statement.

Dr. BOREN. What they were doing was looking at the 168 for the total of everything in spinal cord regeneration and injury.

Mr. CASTEEL. In other words, there were 55 research projects funded for a total——

Dr. BOREN. Yes; research projects in regeneration for $2.4 million.

Mr. CASTEEL. That sounds a lot better.

Dr. BOREN. That's a lot better. We can get more done with that.

Mr. DUNN. If the gentleman will yield, what that means, if you have 20,000 veterans in this situation, which is approximately the number, that you are spending approximately $125 per patient. I think our main qualm that we have is both with the number and in trying to kid this committee, kid the PVA and the public, that it really is a priority item.

Dr. BROWN. We agree, Congressman.

Mr. DUNN. It is not a priority item?

Dr. BROWN. We agree that it is a priority item, and——

Mr. DUNN. Well, your numbers don't seem to indicate it, gentlemen. There's a discrepancy. Less than 2 percent of your budget is not how I define the word priority. I would be glad to go to a dictionary and we'll get it out and look up the word priority. I don't think 2 percent matches it.

Mr. BONER. Are there any further questions that any other members may have? If not, Dr. Brown and Dr. Fonseca, we appreciate your presence here and your testimony.

Mr. BONER. We will now call our next panel of witnesses. That will be Dr. Perkash, Dr. Moeller, Dr. Krebs, Dr. Bernstein, Dr. Cohen, and Ms. McKnew.

Before we begin testimony from the panel, I would like to take advantage of one parochial privilege that I have of being from Tennessee and recognize Dr. Moeller and say that I am pleased to see him here today. I would like to point out to the members of the committee that the Memphis Medical Center has been one of the forerunners in the areas of rehabilitation and research of the spinal cord injured. This facility, which houses almost 160 beds and maintains an 85-percent occupancy rate, is used by all veterans over the mid-South. For each of the past 5 years, the Memphis Medical Center has served more spinal cord injured veterans than any other center in the Nation. I don't doubt that this outstanding reputation can be attributed to Dr. Moeller's dedication to the program.

I have heard from informed sources within the hospital and the Veterans' Administration that he is commonly referred to as Gentle Ben, and that he runs one of the most attentive and warmhearted programs in the country. Although this facility was built less than 15 years ago to accommodate some 50,000 outpatients, the Memphis Center is currently serving over 150,000 veterans.

The superior work being performed by the hospital and the growing need for these services was recognized by the Veterans' Affairs Committee when it enacted legislation to approve the plans for a new spinal cord injury unit in Memphis. I was pleased to learn that the architectural plans are 65 percent complete and construction is scheduled to begin in March of 1983. The new building will be on the ground level to accommodate paralyzed veterans, and the basement will be used as a research center.

Again, it is my pleasure to welcome a fellow Tennessean to our hearing today and we look forward to the testimony from each one of you, especially concerning the spinal cord injury program in Memphis.

What I would like to ask is that we allow each one of you to present your opening remarks. If you have a long, lengthy prepared text, that will be submitted for the record, and we would like to ask that you summarize that. We would like to ask, also, that you hold your remarks to no more than 5 to 10 minutes, and then we will ask questions.

We will start with Ms. McKnew.

STATEMENTS OF LOUISE McKNEW, DIRECTOR, NATIONAL SPINAL CORD INJURY ASSOCIATION, WASHINGTON, D.C.; INDER PERKASH, M.D., CHIEF, SPINAL CORD INJURY SERVICE, VA MEDICAL CENTER, PALO ALTO, CALIF.; BENJAMIN A. MOELLER, M.D., CHIEF, SPINAL CORD INJURY SERVICE, VA MEDICAL CENTER, MEMPHIS, TENN.; MICHAEL KREBS, M.D., CHIEF, SPINAL CORD INJURY SERVICE, VA MEDICAL CENTER, HOUSTON, TEX.; I. KELMAN COHEN, M.D., CHAIRMAN, DEPARTMENT OF PLASTIC SURGERY, MEDICAL COLLEGE OF VIRGINIA, RICHMOND, VA.; AND JERALD J. BERNSTEIN, PH. D., CHIEF, CENTRAL NERVOUS SYSTEM INJURY AND REGENERATION RESEARCH DEPARTMENT, VA MEDICAL CENTER, WASHINGTON, D.C.

STATEMENT OF LOUISE McKNEW

Ms. McKNEW. Thank you, Mr. Chairman. I am not a veteran; nor am I associated with any of the VA programs; so I am not qualified to speak about them. I do come before you, however, as a taxpayer, and as an officer of the National Spinal Cord Injury Association, which tries to do for the paralyzed civilian population what Jack Powell and PVA do so capably for veterans. I also come as an enforced expert on spinal cord injury; my son was injured over 4 years ago and he is now a quadriplegic.

Spinal cord injuries are indeed a VA issue. The Vietnam war alone sent 7,000 young men and women home in wheelchairs. But there are more. This is a national issue, an emergency about which most people, including physicians and Government officials, remain dangerously ignorant.

In the next 24 hours, spinal cord injuries will paralyze another 60 Americans. Over 20,000 people in this country are paralyzed each year, more than used to be paralyzed by polio. Conservative estimates give us a figure of 500,000, not 150,000, Americans with spinal cord injuries. A recent California study permits a reasonable inference that the national figure may be as high as 1.5 million.

This isn't a disease. You don't catch it, and it is not something you are born with or inherit. It just happens. And it is more than just being stuck in a wheelchair. It is an ongoing, life-threatening, painful trauma, an insatiable consumer of energy, time, and psychological resources. The emotional hurt is relentless.

On a case-by-case basis spinal cord injuries are the single most expensive medical problem in the United States today, and I speak from experience. My son's initial hospitalization averaged $1,000 a day. The rehab hospital cost $7,000 a month. The surgeon's fee for his first operation, cost $2,500. Medical deductions filed with my income tax in 1978 totaled $14,000: These were expenses over and above what was covered by high option Blue Cross-Blue Shield. This past year they totaled $24,000.

The indirect costs are also high. Yale University invested over $170,000 to prepare for my son's freshman year. He is the first undergraduate student that Yale has ever had in a wheelchair. The total continues to climb, and so does my debt.

On a national basis, the costs are proportionately staggering. The annual cost to the U.S. Government for the support and care of spinal cord injured persons, including veterans, is approximately $3

billion. That's the Government's contribution. Private dollars add another estimated $3 billion.

And what are we getting in return for this massive, reactive response? In the acute stage patients sometimes receive adequate care, very often suffer destructive care, and rarely enjoy state-of-the-art care. It has been officially admitted that less than 15 percent of the newly injured receive appropriate, immediate, and quality medical attention.

I will skip over parts of may prepared testimony and tell you what appears to be another secret: There is nothing hopeless, incurable, or forever about spinal cord injuries. Despite the paucity of funds, despite the admonitions that paralysis is permanent, despite the lessons they learned in medical and graduate school, researchers have reversed the prognosis for spinal cord injury. They now predict cure. Transplant techniques, genetic engineering, biochemical and neurophysiological discoveries offer unprecedented promise.

Here at the Uniformed Health Services University in Bethesda one neurologist has already proved that paralysis is preventable in mammals. He is now setting standards for human clinical trials which will begin shortly.

In Canada another clinician has been administering cooling techniques to the newly injured, preventing swelling from choking the cord's fibers. The results are exceptionally encouraging.

Indeed, we are on the immediate threshold of permitting thousands to escape the devastating consequences of a spinal cord injury. The treatment, however, must be directed by experts and done so within the first 2 to 4 hours. For those who now live with paralysis, there is extraordinary and well-grounded hope.

Researchers are now grafting short pieces of healthy nerve tissue across injured sections of experimental injuries, bridging or bypassing the bruised portion of the cord. Others are implanting nerve tissue and literally transplanting segments of nerves. Noninvasive chemical and pharmaceutical substances are reportedly permitting long-paralyzed individuals to feel, to sweat, and in some cases to move for the first time in years.

Bioelectronics, an increasingly familiar term, combines our knowledge of biological processes with advanced electronic technology.

Using biofeedback techniques, one researcher is electronically identifying enervated muscles, ones previously diagnosed as useless. Functions have been restored to the point where two young people, discharged from rehab units as hopelessly wheelchair bound, are now walking.

Another research scientist is picking up the brain's signals above the injury, interrupting messages to the legs and, via computer, reinterpreting them for the responsible muscles. His paralyzed kids are peddling bicycles, and he hopes to have them walking within weeks.

Of special relevance to these hearings, you should know that Dr. Bernstein of the VA Research Lab in Washington, D.C., has offered extraordinary hope by applying the lessons of genetic engineering to transplant techniques. He can speak for himself, but I will tell

you that the embryonic nerve cells which he implanted in an adult mammal are growing.

So, you see, the problem has its promise.

However, using the figure of 500,000 persons now paralyzed by spinal cord injury, the $6 billion annual cost to the Nation for care, and an overly generous estimate that we invest $16 million in regeneration/restoration research, we find we are spending, annually, $12,000 per person for care, and less than $32 per person for cure. I think that's fiscal insanity. The lopsided ratio of 400 to 1 becomes all the more skewed in light of the fact that with relatively little money we can reduce the $6 billion national figure substantially and soon.

Last year, the Pentagon was given $20 million to modernize its nerve gas facilities. For $30 million more, this year's program calls for the production of new, lethal weapons that attack and paralyze the body's central nervous system. Something is very wrong when it becomes more important to perfect our ability to paralyze people deliberately than it is to fund promising research that will unparalyze them.

I hope you will reconsider the VA's investment priorities. Theories have yet to be tested, new discoveries have yet to be applied, and clinical trials have been further delayed because of inadequate funds. I ask you, as public trustees, to acknowledge the physical and fiscal benefits that will accrue to us all, veterans and nonveterans, if you aggressively commit to a cure.

Research now offers the guarantee that my son will walk, and you have the power to accelerate his cure. It is not a question of if, but when.

[The statement of Ms. McKnew appears at p. 56.]

Mr. BONER. Thank you. We will have questions, but we will hold them until every member of the panel has had a chance to give their opening remarks.

Dr. Perkash.

STATEMENT OF DR. INDER PERKASH

Dr. PERKASH. Mr. Chairman, I do not have a prepared statement. However, I have some comments and personal observations.

Mr. Chairman, Chairman Mottl has cost doubt on the VA's continuing leadership in research in spinal cord injury and the care of spinal-cord-injured veterans. I would like to reiterate that the VA is still the leader in providing comprehensive care and excellent followup to spinal-cord-injured veteran patients. Over 90 percent of veterans as compared with about 30 percent of nonveterans in non-VA settings are on an active followup program. In addition, the kind of research funding which the VA has provided has been unique. My only concern is that this funding is being reduced. There has to be more funding in terms of dollar value and also more emphasis on the kind of research that can prevent permanent damage to the spinal cord.

I would like to point out, also, that we should not minimize emphasize on research pertinent to problems that the paraplegic and quadriplegic are facing now. The VA's role is to improve the quality of life for the spinal-cord-injured patient, and this improvement

can be effected only by studying the medical problems that these veterans are facing at the moment in their wheelchairs.

I am happy to announce to you that the VA system has accomplished several advances: A new seating system, noninvasivie urodynamic urodynamic techniques, fertility research, new technique for spinal stabilization, and several rehabilitation engineering projects.

My major concern, however, is that we have very few spinal cord injury centers west of the Mississippi. I am a bit disheartened to see that this situation is being perpetuated; that is, proportionately more spinal cord injury beds are being made available on the east coast than on the west coast. I do not mean to disparage Chairman Boner's great new center coming up in Memphis, which is a boon to our cause, when I point out that a map of the United States, showing Palo Alto with only 30 beds to serve one-third of the country—from Palo Alto to Alaska and Wood, Wis.—brings up the contrast between the east and west coast; 8 or 10 years ago, when I joined and planned the center at Palo Alto for the veterans, almost within 1 month I had to submit the blueprints for 30 more beds. I don't know why the addition of 30 more beds in Palo Alto has been postponed for such a long time when we face every day in Palo Alto a waiting list of 35 to 40 patients on the average. I am not suggesting that we are not taking care of the urgent problems, for we are taking care of all the patients who have urgent problems every day as best we can. What I mean to say is that we are not providing the optimum service that I would like to provide.

Thank you, sir.

Mr. BONER. Thank you.

Now, Dr. Moeller, would you proceed.

STATEMENT OF DR. BENJAMIN A. MOELLER

Dr. MOELLER. Chairman Boner, I would just like to thank you and your colleagues for making possible the work of the VA's spinal cord injury centers.

Mr. BONER. Thank you, Dr. Moeller.

Dr. Krebs.

STATEMENT OF DR. MICHAEL KREBS

Dr. KREBS. Chairman Boner, I have a prepared statement that I would like to read.

I am the chief of a relatively small spinal cord injury service, 22 beds, which is part of a major teaching hospital of the Baylor College of Medicine System. I am a full-time geographic faculty member of the departments of physical medicine and rehabilitation.

One of my special academic interests is the training of specialists in physical medicine and rehabilitation. I am the chairman of the graduate education committee of the department of physical medicine. Since I became chief of the spinal cord injury service at the VA Medical Center, Houston, approximately 2 years ago, this service has been made an integral part of the residency training program of the department of physical medicine. My assistant chief is also full-time faculty in the department of physical medicine and

together we supervise a physical medicine resident physician who is regularly assigned to the service.

Our service philosphy can be expressed as two basic objectives: No. 1, the rehabilitation of acute spinal cord injured veterans. Generally, three-quarters of our inpatient beds are occupied at any one time by this type of patient. Our goal here is the restoration of the individual veteran to the maximum level of independence consistent with his degree of disability and medical condition.

No. 2, the provision of health maintenance for chronic spinal cord injured veterans. This consists of primary prevention of complications associated with spinal cord injury by long-term follow up in the spinal cord injury outpatient clinic, and a readmission of selected cases for treatment of complications which require intensive medical care.

The spinal cord injury service carries out its mission as an interdisciplinary team. The staff works as a unit with the patient accomplishing the goals of maximum independence or health maintenance.

The spinal cord injury service at Houston depends upon other hospital services to provide the needed personnel for this rehabilitation team. These health care professionals remain administratively part of their parent service but must develop a group identity, including shared goals and an effective working relationship in order to meet the unique requirements of the spinal-cord-injured patient.

It is my pleasure to direct a small but highly competent and dedicated group of health professionals who are attached to the spinal cord injury service. This includes rehabilitation medicine, service therapists, psychologists, and social service workers. However, the physicians and these professionals can only do so much when it comes to rehabilitation of the newly injured patient. Much of the patient's day-to-day rehabilitation in the medical, psychosocial and physical spheres is carried out by the nursing service. Most of the hands-on care of the spinal-cord-injured patient is delivered by nursing assistants. In view of the present national shortage of registered nurses, this situation is not likely to change soon.

The ideal nursing assistant caring for spinal-cord-injured patients should be expected to provide specialized care and be able to exercise judgment based on knowledge of the patient and his or her disability. In order to insure that the veteran with spinal cord injury receives the level of care he or she requires, the nursing assistant must have adequate training, recognition, and opportunity for advancement.

In my opinion, based on my experience at the VA Medical Center, Houston, the performance and morale of the nursing assistants of the spinal cord injury service leaves something to be desired. I believe that the philosophy of nursing administration here, that nursing assistants must be tolerated only until such time that enough registered nurses are hired to replace them, is responsible for the lapses in patient care which occur.

The job of a nursing assistant on the spinal cord injury service is not an easy one. It is physically demanding as well as emotionally draining. I feel that the majority of our nursing assistants are satisfactory, with a few who are truly excellent. However, I find their

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morale, in general, is poor. This, of course, has a carryover effect in their attitudes toward patients and rehabilitation tasks.

The good nursing assistants feel that their accomplishments are not appreciated, while poor nursing assistants have little or no motivation to improve their performance.

At present, there is no chance for grade advancement in the nursing assistant series while continuing the care of spinal-cord-injured patients. The nursing assistant who demonstrates his or her capability by virtue of knowledge, experience, and consistent performance should be eligible for advancement beyond step increases. Having reviewed the position classification standards for the nursing assistant series, I realize it may be difficult, if not impossible, to provide for advancement of nursing assistants through a redescription of their duties. Therefore, I suggest the establishment of a new position classification of spinal cord injury rehabilitation technician. If done in the proper way, this would provide an opportunity for a superior nursing assistant to advance beyond the grade of GS-5, which is now the upper limit of advancement in the nursing assistant category.

Nursing assistants who wish to make a career out of spinal cord injury rehabilitation would have incentive to aspire to the increased education, increased recognition, and pay status of a rehabilitation technician. Continuing education courses traditionally offered only to health professionals could be devised for such personnel as well as inservice programs.

As a precedent, there is presently in the VA Department of Medicine and Surgery the position of rehabilitation technician for alcoholism at a GS-7. This position requires 5 years of experience, only 3 of which are in the area of alcohol rehabilitation, with no special educational qualifications. If the Veterans' Administration is serious about providing quality rehabilitation to the spinal-cord-injured patient, I feel it should at least make the effort to provide the same quality of personnel who carry out the rehabilitation of alcoholics.

I share this information with the committee in the hope of improving the situation of the nursing assistant in the spinal cord injury service, those with the least status on the spinal cord injury service, but often who matter the most to the patients, so as to provide better care for our patients.

Thank you.

Mr. BONER. Dr. Cohen.

STATEMENT OF DR. I. KELMAN COHEN

Dr. COHEN. Mr. Chairman, I would like to thank the committee for the opportunity to speak to you this morning and to tell Mrs. McKnew that as a professor in a medical school, if I had the opportunity to award an M.D. degree, I would award it after your comments. Much of what she said I think, is elegant and really summarizes a lot of the things that I had to say.

Rather than read my prepared text, I would like to make a few comments based on some remarks that were made.

In 1982, I think we have the methodology and the creativity to reduce the cost and greatly improve the care of the spinal cord

injury patient, and this includes several areas of research. I can really only comment on that in which I am involved and spark my interest.

One of the things to mention is, I think, the funding of this is the key problem, and based on the remarks that you made, Mr. Dunn, let me make the comment that VA funding, to the best of my knowledge, is on work done at the VA, where the research is done at the VA. I, myself, have a very active wound-healing lab at the Medical College of Virginia; it is about 5 or 6 miles from the VA. I have never applied for VA funding simply for the reason that I think it would be an absolute duplication of research funding or research allocation of space and technicians to set up two operations. And yet, if I apply for VA funding, my research, I am told, would have to be done at the VA. I think this is a problem that, if it really does exist to this degree, you should address.

There is no reason, if a university is affiliated with a VA hospital, that even though the clinical research may be done at the VA, that the funding can't be allocated so it is done at the base university. That, to me, is absolute foolishness. So my own particular spinal cord injury research is being funded right now by the PVA.

The third——

Mr. DUNN. Can I interrupt you there? Could you make that point one more time?

Dr. COHEN. Sure.

I have my laboratory at the Medical College of Virginia. I wanted to do some research on spinal cord injury patients, wound-healing research, OK? I do not have a laboratory at the VA hospital, or technicians at the VA hospital. The VA funds research which is done basically on home base, at the VA hospital.

For me to apply to the VA for funds and set up new equipment, new technicians, et cetera, at a separate facility 5 miles away, is idiocy. Therefore, the sources I would approach for funding have not included the VA, because I don't want to set up a second research facility. It is foolishness. I have got probably NIH-funded equipment that amounts to $100,000. It would be absolute duplication. So I think this is an issue that you probably should consider, and I didn't think about it until I sat in the room and listened to this. Therefore, the sources of funding I went to were PVA and the NIH.

I have no sour grapes with the NIH because I receive a lot of money from them each year, over $100,000 for related wound-healing research. One of the problems with NIH is the taking on of new projects, and even though you're an established investigator and well funded, the way the NIH seems to work is they would like a lot of solid data before they fund you. So even though I am a well-funded NIH investigator, one needs some really decent baseline data before NIH is going to cash in their chips and invest in you. I can understand that. Dollars are tight. So I have received seed money from PVA to really get me started over a couple of years in the work I am doing with wound healing in spinal cord injury patients.

My main point to you is that it seems to me the VA shouldn't fund people who are only located at the VA, but within the university system, should be able to fund those who can best do the job.

I got the point with the testimony before that perhaps only 2.5 was going to spinal cord injury research because maybe that is only the number of grants they were getting. If every grant they are getting is funded, you have to wonder about the system; 100 percent of the grants can't be that great, and if they were funding within the systems, I think that would be helpful.

Anyway, now that I made that little——

Mr. DUNN. That was a good point.

Dr. COHEN. Now that I have made that little bit, let me go on to say that I have listed five areas where I think there really are some hot things that can be done.

One is pharmacological control, and you have already mentioned that in animals one can reverse the acute effects of spinal-cord injury. I don't think it is a dream at all to say that within the next 5 or 10 years we will have paramedics who see you on the street, when you have had your accident, and can inject you with one of these magic bullets that are pharmacologically being worked on now—and they may not be able to totally reverse it, but they are really going to be able to cut down on the degree of deformity and injury you have from the initial trauma. So I think that is exciting.

The second area is regeneration, and this is being approached in many, many ways. In our own laboratory at the medical college we are approaching this by trying to prevent collagen—which is the material that clogs up the pipe, so to speak, when the cord tries to regenerate—from getting into the spinal cord and allowing for regeneration. So there are many approaches to this and I think it is terribly exciting.

You, by the way, can take an animal who would normally heal by scar and never regenerate a limb, prevent the deposition of collagen and the limb will grow. So this kind of stuff in man is not science fiction. It is something you should be terribly interested in, and it is something that I think we will see within the next decade or so.

As far as pressure sores, the decubitus, which is the main vein of the spinal cord injury patient and a terrible problem for these patients, we are working on that problem, sponsored by PVA, to try to understand the healing process and try to reverse some of these things. Everyone blames this on pressure, and lousy nursing care, and the patient not taking care of himself. We really don't think that's the case at all. We think the fact that the patients are denervated actually alters their healing capacity, and there is a fair amount of evidence for this. With PVA sponsorship we are studying this now at the McGuire VA in Richmond.

The other area that you have already nicely covered, and it is something that is coming and I think the VA should put their money into it because it is practical and we can do it today—and no one is really doing it on a large scale—that is the reinervation of these patients, with the state-of-the-art, with what we can do surgically today, and that is taking nerves and transplanting them and moving them and at least giving these patients sensation and some motorability.

Finally, the psychological aspects in the care of these patients I still think needs a lot of research and a lot of help and a lot of bolstering to improve the quality of their life.

Finally, I added the attraction of physicians to research. The amount of take-home money, if you compare it with private practice, or even university salaries and VA's, it is low at the VA. I agree with what was said, that you can sure lure people to work for a paltry sum if they have good research abilities and facilities, and that will attract people of fantastic docks to the VA if they are given this opportunity.

Just a comment about the quality of care and I'll leave out the specialty of plastic surgery. I would like to agree with Dr. Krebs, that in Richmond we find the lower level personnel just get trained, they're good, and they go off and do another job because they are underpaid and undertreated.

As far as the spinal cord injury of the elderly go, I would like to submit that we feel in Richmond, rather than being at geriatric kind of centers, we would like to be able to take care of their spinal cord injuries at our own center. This is the chronic patient. A patient of 70 with a wound is no less a problem than a younger patient. We feel that for the best expertise and surgical care they should be at surgical units and not scattered. For example, in Virginia they go to Hampton VA and not to the Richmond VA. So we feel that, having this specialized center, that we would like to see the patients there.

I would also like to comment about your remarks about attendant care. The VA in Richmond has the greatest expertise in the State of Virginia, for example, in the care of these patients. If we could train attendant care, to go out into the community when these people are home, for veterans and civilians, my God, we could cut down tremendously on the number of admissions if they were properly educated and taken care of at home. The VA has the ability to do this, I think, and it could be improved.

I also think the VA has a responsibility to educate the private sector. The care at the VA for spinal cord injury patients at Richmond is far superior to anything in the community, including my own university hospital. If anyone in my family were to have a spinal cord injury, I would want them treated at the McGuire VA Hospital because it is far superior to any other facility in our entire area.

In summary, I would just like to say that the Federal Government has spent a tremendous amount of money putting a man walking on the Moon. I think, for far less, in the way of capital outlay, we can have our spinal cord injury patients walking again, and that your commitment to this objective will be far more beneficial to far more people than the guys we send up on the Moon.

Thank you.

[The statement of Dr. Cohen appears at p. 59.]

Mr. BONER. Thank you.

Dr. Bernstein.

STATEMENT OF DR. JERALD BERNSTEIN

Dr. BERNSTEIN. I am Dr. Jerald J. Bernstein, a neuroscientist, chief of a Veterans' Administration laboratory dedicated to basic research on mechanisms of spinal cord growth or regeneration after injury. I am also a professor of neurosurgery and physiology

at the George Washington University School of Medicine. I have done spinal cord regeneration work for 25 years and I am the author of over 125 research papers, chapters, and books on the subject of regeneration of the spinal cord.

I am testifying as an expert in the field of spinal cord regeneration. I would like to testify that basic research in paraplegia is as important as rehabilitation, since basic research can develop real treatment to alleviate this great emotional and financial burden for society.

In the early 1970's, at a conference on regeneration in the nervous system, the scientists at the conference concluded that a cure for paraplegia is amenable to basic research. This was remarkable.

One, it occurred only 10 years ago, so research is relatively new in this area.

Two, it was an admission by the biomedical community that a cure for paraplegia could be obtained from knowledge gained in the research laboratory.

Three, this statement now placed a research emphasis on the problem of paraplegia. This emphasis has resulted in the establishment of laboratories with expertise in regeneration. It takes 5 to 7 years to establish such a laboratory, and it takes 4 to 7 years to integrate a young M.D. or Ph. D. into basic science regeneration research. Because of these efforts, the information base is expanding and has increased enormously in volume over the last 5 years. The young people who were trained during this period are now beginning to make their contribution and impact.

In the past 5 years we have discovered some very exciting facts about the nervous system of mammals—after injury of the spinal cord, the nerves continue to grow. These new nerve fibers are side branches of the injured nerves. Unfortunately, these nerve fibers do not grow across areas of damage, but experiments to reconnect the lower spinal cord around the damaged area are being studied.

We have also found that if new nerve side branches or nerve sprouts can be grown into different areas of the nervous system, these new nerve fibers could form connections and, in essence, "talk" to other nerve cells. Information appears to be transferred between the nerve cells. However, we do not know if this exchange of information can result in the return of function.

A most exciting area of research on spinal cord regeneration or regrowth after injury is the field of spinal cord transplantation which is now underway in our laboratory. Please do not think that a spinal cord can be transplanted from one mammal to another. However, a form of biological engineering is possible. There is only, in essence, a single set of nerve cells per mammal and human beings. At 2 years of age, the human being has all the nerve cells he will ever have. These nerve cells will grow longer as the body grows, but they do not divide or replace themselves.

We are exploring whether the injured spinal cord be aided by the introduction of fetal nerve cells, so they can be made flexible and make meaningful contacts. Our laboratory has transplanted the nerve cells from fetal mammals whose nervous system is not mature into an adult animal spinal cord. These studies show that the newly introduced nerve cells, which we can identify, are now incorporated into the spinal cord of the adult. In essence, we have

now given the adult injured mammalian spinal cord a source of new nerve cells and conditions which originally resulted in growth during its development. Many experiments must now be performed in order to ascertain if these new nerve cells can restore function in injured spinal cords.

Research is a time-consuming process which cannot yield immediate answers. We have just initiated these experiments which have been in the planning stages since 1979. It took us 8 months to learn how to properly do the fetal transplants and we are now preparing our first scientific publications which might be published in 1983. From conception to initial publication, 4 years have elapsed. Even in this timeframe, this research is just beginning. Only with sustained long-term funding can the research continue.

This transplantation research is only given as an example of the exciting research that is underway in the field of spinal cord injury. There has been an explosion of information leading to innovative experimental approaches to solving the problem. However, research not only involves the mechanics of doing the work, but also the participation of new young scientists in the process. The young M.D. or Ph. D. doing research in this area is invaluable to me, since students and young investigators produce new ideas for innovative research as a result of the interaction with established scientists. This is the most valuable resource in science. A branch of science requires a critical mass of scientists to move it ahead conceptually. The insight into the problem of how to make the injured spinal cord regrow will come from this interaction. The funding of research not only facilitates the mechanical aspects of getting research accomplished, but brings young minds with fresh ideas to work on the problem.

The answer to regrowth of the injured spinal cord can only be found through basic research. I urge you to support regeneration research to the maximum in order to maintain our momentum, expand the field by attracting young scientists, and to increase our knowledge through a new information base. It is by this mechanism that we can get paraplegic and quadriplegic veterans who have served in the military of our country and all paraplegic and quadriplegic citizens of the United States out of their wheelchairs.

Thank you for your attention.

Mr. BONER. Thank you.

We have several questions we want to ask. Mr. Dunn, do you have any you would like to ask first?

Mr. DUNN. First let me compliment Dr. Krebs for being willing to be critical of the "hand that feeds him." I appreciate that kind of testimony. Also, in going one step beyond that, in not only being critical but also suggesting some alternatives for the VA. Believe me, we will follow up on your suggestions.

For Dr. Bernstein I have a question. You talk about attracting young talent. We had testimony earlier about things the VA was not doing to attract and keep good people.

Would you agree that that is a problem area that the VA has not addressed, and if you would agree, how can we turn that around?

Dr. BERNSTEIN. I feel the VA must address the problem and make more career slots available for young Ph. D.'s and M.D.'s doing research. In my own problem now, I have talked to you about

this implantation research. The person who did the research with me is going to leave, and they are going to leave because the grant that they wrote was not funded, and their salary is attached to the grant.

I have another person who has been working with me for 9 years. They now have a merit review in, which results I don't know, but they tried to get funding from other agencies and they have never been able to be funded. They were too young, they had some problems, and their salary was attached to this money. The man is 30 years old. Can you imagine being 30 years old, having to write a research grant every year-and-a-half, and your wife is having a child. You can have no way to spend your life in this manner until you're 65 years old, trying to find a mechanism to do research. Now, how would we bring people like this into the VA?

I think our biggest problem is to identify innovative research. The VA has been looking into these problems in other areas, but if we have an innovative research program which is set up, where the program is set up so that someone says yes, this is, in quotes, a "flier," but look at the yield it could have if it works, and the way to accomplish this is to get a young M.D. or Ph. D. interested in the problem, to have a marriage between the established investigator and a young M.D. or Ph. D. on a program which is innovative, in research terms, is absolute dynamite. It would be the way to now pursue this through this individual.

The other way that may be able to be used is to have a program whereby young M.D.'s and Ph. D.'s spend time together of 6 months in the spinal cord injury center, in the clinic, and then 6 months in the basic research laboratory. After this time period, they get together with two senior investigators and write up a research proposal which they have seen the need for first hand.

The hardest problem in reality, if I could use this example, in raising a child, is when they bring you a problem you know it won't work, and you go and say it won't work. Well, these two people who often propose things, which you know don't work, and just like with your children, miracles happen. It works. For what reason, it is beyond our comprehension. We don't understand.

So the way to get this new innovative research and get these new people in perhaps is to instill a program of this sort. But we must, I think, as in nursing and other things, make adequate career opportunities for people in research and in that way we will keep them working on the problem.

Mr. DUNN. Are you saying to me that while the hierarchy of the VA is willing to call this type of research a priority, you would disagree it's a priority?

Dr. BERNSTEIN. In their view it's a priority, and they have funded it like it's a priority. But you can't have more proposals unless you get more people. You see, you need a critical mass.

Dr. COHEN. Can I make a suggestion?

Mr. DUNN. Sure.

Dr. COHEN. You know, I'm a plastic surgeon who fortunately went to NIH for 2 years instead of Vietnam, OK? That's what really turned me on. I was with a bunch of basic scientists and that really got me started and it is why I do what I do today, which research-wise is fairly creative.

There is no reason why the VA can't set up a program very similar to NIH, with career research development awards, which take bright, young people, put them in an environment similar to what I had at NIH, which is the opportunity to work very closely with a super basic scientist, and get turned on, and allow this kind of thing. Say, "Listen, for the next 5 years, we have picked you out as a .400 hitter and we're going to let you play in the league with us," and let that guy's career grow and develop.

The $12,000 a year salary I made during my 2 years, each year at NIH, that the Feds invested in me was one hell of a fine investment. It really launched me off to a career in science. There is no reason, in 1982, why you can't take good people, pick them very selectively within the VA system, and put your money on some really good horses and invest in a 5-year career development award the way NIH does. Pick them carefully, but pick them.

Mr. DUNN. I thank the gentlemen for their comments.

Mr. BONER. I am going to ask for a response from any member of the panel who feels so inclined to do so. If no one responds, I will call on someone.

It has been indicated that the nursing turnover is very significant in the SCI centers, particularly if the nursing personnel have reached a point of skill which makes him or her a more valuable commodity. What would you suggest the VA do to retain these highly specialized personnel?

Dr. KREBS. Pay them more.

Mr. BONER. Do you have any other suggestion than money?

Dr. COHEN. Stroking.

Mr. BONER. Dr. Moeller, being an administrator, do you have any other suggestions?

Dr. MOELLER. I think the statement of "stroking" is most important, to recognize these individuals and their remarkable contribution in the face of drudgery, which would enhance—I, myself, need to do a better job of that.

Mr. BONER. Dr. Cohen, you indicated that your spinal cord injury research is funded by the Paralyzed Veterans of America. I think this is significant because the patient is paying out of his own pocket for research which could lead to the improvement of his own condition.

Has the VA given you any support in your research, financially or otherwise, and what percentage of your research funding comes from private sources and how would you view the need for additional funding from the VA?

Dr. COHEN. Well, as I explained in my initial statement, I did not apply to the VA for research funding sources because my laboratory is 5 miles down the road at the Medical College of Virginia. I think this is a deficit, that if a university-affiliated program has a laboratory that benefits the VA problem such as spinal cord injury, there should be a system where VA funding—where the money can be dumped as far as the mechanical research goes within the university. I think that would improve the quality of the research projects which would reach the VA.

What was the second part of the question?

Mr. BONER. What percentage of your research funding comes from private sources.

Dr. COHEN. At present I don't have any research funds from private sources. All of my funding comes from the National Institutes of Health and it amounts to about $150,000 a year. The PVA grant is about $40,000 a year.

Now, the PVA grant would be impossible if it wasn't for the NIH funding. The reason that this grant is not ready for NIH—and I am sure you can go along with this—is that I really don't have enough data. It's a "flier," that I'm doing. It is going to take 2 years before I have enough data to really convince an NIH group that this is worth them investing $100,000 or $150,000 a year. Having been on the other side of the fence and having sat on NIH site visit and study groups, their budgets are extremely tight and they have to put their money on the mark that they think is really going to pay off. So the NIH is extremely cramped for funds.

I think the private sector is difficult. If you go to industry, they usually want you to solve a problem that is going to benefit them very directly. That's not the way research should go.

Dr. BERNSTEIN. Can I just add one thing.

I hope you gentlemen heard this gentleman's figures. It takes between $150,000 and $250,000 a year to run a laboratory. This is what the cost is. The cost keeps on going up every year, and we keep on discussing about the National Institutes of Health. Gentlemen, I just, after 18 years, lost my funds from the National Institutes of Health. It is simply not there any more. So I am funded by the VA and I have to get other funds from other areas.

I cannot tell you how much time we spend writing to get funds. It is a matter of months. We have just spent 9 months on having three different people write grants in my laboratory.

Dr. COHEN. You know, the amount of time trying to get funding is astronomical. You can ask my wife who is sitting back there about weekends. I'm just never home. I am writing grants. It just goes on and on and on.

On the other hand, I think peer review is superb, and I think that junk should not be funded. But the NIH study groups—and I have been on them—will say to you, "My god, we fund 40 percent of the projects as super grants, and 5 or 10 percent are actually getting the money." They are approved but they are not funded. So there is a lot of science going down the drain.

It also hurts the young guy coming up. I will have a resident who is interested in research, and he says, "My god, boss, they're only funding 10 percent. How am I ever going to get started? The day of research is dead." So when you look at these young people coming up, who need encouragement, they don't see the sources to get it. This leads to them going to the private sector and no research.

Mr. BONER. Dr. Perkash, are you experiencing an overcrowded situation at the Palo Alto SCI center?

Dr. PERKASH. We have run a 95 and 97 percent occupancy rate for the last 7 years. We have taken another 8 or 10 patients in the rest of the hospital, which means that we do take care of all emergency patients, but the patient care in other wards for this kind of a specialized patient is not optimal.

Mr. BONER. What would you suggest to try to correct some of your problems out there in this area?

Dr. PERKASH. The VA central office has an approved project for us for 1985, for expansion to 60 beds. I wish it could happen a little earlier. The problem is today. We need 35 to 37 people to be treated, and they cannot be transported 2,000 miles away to the east coast where beds are available.

Mr. BONER. Let me continue in this line of questioning just a moment.

Could you discuss your staffing needs with the subcommittee and, included in your discussion, would you respond to these questions: Are you experiencing a high turnover of nurses; have you tried or suggested any alternatives to the central office to recruit and retain qualified health care professionals for the SCI centers, and if so, what has been the response from the central office?

Dr. PERKASH. Our turnover rate of nurses has not been as bad as compared with other areas in the country. We have tried to develop some incentives such as sending them to various meetings, and again PVA and some other sources have helped us to provide those incentives, to upgrade their interest in the SCI patient care at Palo Alto.

We do have a problem from time to time in hiring therapists and other staff on the SCI service, in an area that is very expensive to live, where the housing market is out of this world. Filling any position is a problem from time to time. There is no special grade—it always needs another year of VA study before anything can be accomplished for filling slots in the scarce category.

Mr. BONER. Dr. Krebs, what has been your experience with overcrowding at the Houston SCI Center?

Dr. KREBS. At present we have an acute bed shortage. We have a full capacity right now, and we have several patients on other services and we have an admissions list of approximately 12 patients. Approximately half of those are acute injuries, needing initial rehabilitation, and the other half have either followup rehabilitation or health maintenance needs.

Mr. BONER. What are your staffing requirements, and have you had any experiencing with nursing service shortages?

Dr. KREBS. We have had considerable experience with nursing shortages, particularly with the head nurse position being open for several months, but it has been recently filled. However, we have several staff nursing positions open.

Mr. BONER. How would you retain and recruit the personnel needed to provide this care if you had the opportunity to do so?

Dr. KREBS. I would request that more flexibility be used in establishing incentive pay, that special recognition or a specialist designation be given to certain RN professionals, and that the nonprofessional or nursing assistants also be given some type of specialist designation and appropriate increase in pay, as well as the opportunity for special education in spinal cord injury, not to move them up and out of nursing assistants but to make them better nursing assistants.

Mr. BONER. Do you foresee the need for a new SCI center and additional beds in the State of Texas?

Dr. KREBS. Yes, I do. I think the figure that the central office has obtained supports this overwhelmingly.

Mr. BONER. Dr. Moeller, what is your perception of the current state of SCI health care, based upon your knowledge and long years in the field of such care?

Dr. MOELLER. The spinal cord injury care in the VA has improved as the years have gone by. We stress more the team concept, especially the psychosocial angle, which in the long run means more than much of the medicine we hand out.

At Memphis we do have two physicians working on spinal cord injury connective tissue cells, trying to add to the knowledge of the potential day when the spinal cord can be induced to function again.

I think the services have improved over the years, and they are much better than they were when in 1948 I first started working with them.

Mr. BONER. Thank you.

Are there any other statements that any of our panel would like to make before we conclude the meeting? If not, I want to thank you for your well-balanced views on patient care, education, and research. It has been and will continue to be a great help to this committee.

Our thanks to each of you for taking the time to be with us this morning.

[Whereupon, at 11:35 a.m., the subcommittee was adjourned.]

APPENDIX

STATEMENT OF R. JACK POWELL, EXECUTIVE DIRECTOR, PARALYZED VETERANS OF AMERICA

Mr. Chairman and Members of the Subcommittee, it is a privilege for me to appear today to present the views and concerns of Paralyzed Veterans of America concerning the Veterans Administration's Spinal Cord Injury (SCI) Program. PVA is a Congressionally charted veterans' service organization, whose 12,000 members are veterans who have experienced spinal cord injury or dysfunction; therefore, PVA is greatly concerned with the present and future provision of services to all SCI veterans.

PVA's goals as a national organization can be summarized as twofold. First, PVA wants to see the best possible health-care services provided to all spinal cord injury patients, both veteran and non-veteran. Second, PVA is actively and urgently working to ensure that a cure is available for those who incur spinal cord injury in the future. These two goals are essentially the reason for PVA's founding shortly after World War II. Prior to that time, the mortality rate for those who had incurred spinal cord injury was such that their life expectancy was limited to from one to five years. Because of the low life expectancy, the state of medical knowledge, and differing priorities for research and investigation, no integrated overall program of care for SCI patients was considered necessary.

The many changes arising out of World War II in the social, economic, and medical fields were to combine, and were to present SCI veterans of that conflict with a more optimistic future. These individuals were at first known as "paraplegics," a term of general use to cover paraplegia, quadriplegia, and the non-traumatic spinal cord injury dysfunctions. Estimates are available concerning the actual number of veterans who incurred and survived SCI during World War II: PVA's information indicates that approximately 7,000 members of the United States Armed Forces experienced spinal cord injury during World War II. Of these individuals, it is estimated that some 2,500 survived initial injury and reached general medical facilities.

That even this number were kept alive for an extended time was a tribute to the medical profession's contributions to the nation's war effort, and to the armed forces' improvements and advancements in methods of handling and caring for the wounded. The result was obvious, though, and there was a significant number of SCI veterans in the military and Veterans Administration hospitals.

These stabilized SCI patients presented a challenge to the medical profession because their conditions were frequently complicated by critical pressure sores, urinary tract infections, and other diagnoses that required stabilization before any other treatment could be considered.

The solution to these unique problems was to collect those veterans who had experienced spinal cord injury in special hospitals designated to receive them, and to provide for concentrated, multidisciplinary medical care and treatment. In the East the veterans were brought to England General Hospital which was a string of hotels on the boardwalk at Atlantic City, New Jersey, which had been commandeered by the military. After medical stabilization they were sent to locations closer to their homes, whenever possible. Hospitals to which a number of SCI veterans were Cushing (Boston, Massachusetts), Haloran (Bronx, New York), and St. Albans (New York City). Other hospitals where SCI patients were concentrated were Vaughan Hospital near Chicago, Illinois; McGuire at Richmond, Virginia; and Kennedy at Memphis, Tennessee. On the West Coast, SCI veterans were processed through McCaw Army Hospital in Walla Walla, Washington, Dewitt Army Hospital in Northern California, Hammond Army Hospital in Modesto, California, and Bushnell Army Hospital in Brigham City, Utah. These SCI veterans were eventually placed at the Birmingham, California, Hospital and the Corona Naval Hospital in California.

Paralyzed Veterans of America was formed by the SCI veterans of World War II who were hospitalized at these locations. PVA records indicate that the first organi-

zation of SCI veterans took place at the Birmingham Hospital in California; the groundwork was done during 1945, and the group was formally chartered by the State of California on March 7, 1946. The formation of similar groups with the same goals was also taking place at the Halloran Hospital, which led to the start of the Bronx and the St. Alban's Chapters. Also, patients at the Vaughan, Cushing, McGuire, and Kennedy VA Hospitals organized local groups resulting in the eventual establishment of nine associations of paralyzed veterans organizations in the United States.

The actions of these individuals groups coalesced on February 7, 1947, when delegates from seven of these local organizations met at Hines VA Hospital (Vaughan Chapter) to form a national organization. SCI veterans from hospitals located in California, New York, Illinois, Tennessee, and Virginia attended this first meeting. The group from Cushing Hospital in Boston, Massachusetts, indicates their interest in joining the proposed national organization. This Chapter had slightly over one hundred members, but none could attend the meeting because of a lack of finances. The result of this meeting was the formation of the Paralyzed Veterans Associations of America (later changed to Paralyzed Veterans of America) with nine local Chapters. PVA was incorporated under the laws of the State of Illinois on April 14, 1947.

The First Annual Convention of PVA was held in September 1947, at the McGuire VA Hospital in Richmond, Virginia. Although the delegates had to develop the guidelines and procedures by which the new organization would operate and grow, they also got immediately involved with issues concerning the Veterans Administration. A quote from an early history of PVA is illustrative of concerns and thoughts of these first PVA members:

"The convention went on record urging the creation of domiciliary care for the NSC in the VA hospital system; liberalization of the auto grant to enable eligibility for quadriplegics; promotion of a Congressional Charter for PVA; the standardization of procedures for transporting the disabled aboard all national airlines; and, the creation of a special spinal cord research foundation. Bob Moss reported that he had written to the Veterans Administration in late 1946 urging the creation of an Office of Coordinator of Paraplegic Affairs. The idea was enthusiastically supported by the convention. He also noted that the VA had been cutting the staff of the vocational guidance and rehabilitation service."

The Second Annual PVA Convention was held in September 1953, at the Kennedy VA Hospital in Memphis, Tennessee. This meeting ratified the proposal to create a separate spinal cord research foundation to develop a PVA research program. Total PVA membership at that time was 1213 members. Again, a quote from a PVA history illustrates the concerns of the members:

"President Moss reported that a letter from VA Administrator Carl Gray, dated February 10, 1948, had (1) rejected PVA's request for the creation of a Coordinator of Paraplegic Affairs in the Central Office; (2) refused to recognize PVA for the purpose of representing claims of members; (3) refused to support paraplegic housing; (4) denied that reduction of personnel on SCI wards was affecting quality of medical care; (5) refused to advise field offices on the type of prosthetic equipment which should be furnished to paraplegics, and (6) rejected PVA's proposal that SCI personnel be permitted to visit other SCI centers to broaden their knowledge."

It must be remembered that during this period hospitalization for initial treatment of spinal cord injury averaged from two-and-one-half to five years. However, PVA members were fighting for the concept of rehabilitation of the SCI veteran by the VA health-care system, with an ultimate goal of re-entry into the mainstream of daily life. The early PVA members knew that they were considered "different" by the general public. Whether it was the injury, the wheelchair, or the attitudes of the "outside" world, these SCI veterans realized they were pioneering a new trend in medicine, and they had to promote the planning and processes which would return them to as normal a life as possible.

Without the efforts of these World War II SCI veterans, the VA SCI Service would not exist today. They cared enough to fight for their wants and needs and to make the VA respond. Since those early years, PVA has recommended programs which were, and are, essential for the lives of the spinal cord injured veteran and non-veterans as early as 1946 and 1947 the ultimate need for domiciliary and nursing home care for aging veterans was promoted. It took the VA 17 years to initiate that program. In 1946 a call was made for the creation of a Coordinator of Paraplegic Affairs. This request was fully supported by the first PVA convention. This position did not become a reality until 1951 when a special committee, appointed by President Truman to investigate the VA health-care system, made a position recommendation. PVA at that time also succeeded in getting the use of the prosthetic card for the SCI veteran. Starting in 1954 PVA promoted the establishment of a

separate Spinal Cord Injury Service within the VA. This goal was finally achieved in 1970.

The Spinal Cord Injury Service which was created had 11 Spinal Cord Injury Centers in VA medical centers throughout the nation. Since then, the SCI Service has expanded to 19 SCI Centers. The latest SCI Center to open was at the Augusta VAMC in Georgia. This unit was officially opened in January of 1981.

This system to specialized VA care for spinal cord injured veterans is the only such comprehensive program in the United States. A Department of Medicine and Surgery Fact Sheet on the SCI Program shows that during Fiscal Year 1980 the VA SCI Program treated 7,063 in-patients and 30,000 out-patients in Spinal Cord Injury Centers. The geographic distribution of these centers are shown in the following map.

Location of VA SCI Centers

PVA's Research Program has been working with Dr. Juan Fonesca, VA Director of SCI Service, on developing current information of the SCI veteran population. The information as it becomes available, and projections based upon this information, should greatly assist the VA in this area of patient care.

There are a number of significant findings which should be highlighted in any discussion of the needs of aging veterans. Most SCI veteran respondents to questionnaires, which PVA mailed to 97,889 potential spinal cord injured veterans, served in World War II (51 percent) and are over 50 years of age (64 percent). Sixty-four percent (64 percent) of all the SCI respondents are service-connected disabled veterans, while 35 percent are non-service connected. The most positive finding from the survey responses was that 67 percent use VA facilities. Unsurprisingly, 97 percent of all SCI respondents were men. The largest group of responding females served in Work War II. These results do not differ greatly from those reported for the general veteran population.

One finding which does differ from general veteran population trends was the geographical distribution of the SCI veteran. The top ten states of residence for veteran respondents, compared with that of the general veteran population, are:

SCI respondents

California	10.0
Florida	6.8
Texas	5.9
New York	5.6
Pennsylvania	4.9
Ohio	4.9
Michigan	3.2
Illinois	3.0

Massachusetts	3.0
Wisconsin	2.6

General veterans population

California	11.2
New York	8.1
Pennsylvania	5.8
Texas	5.5
Illinois	5.1
Ohio	4.9
Florida	4.5
Michigan	3.9
New Jersey	3.7
Massachusetts	2.9

Other pertinent facts learned from the SCI veteran respondents are also presented:

Total SCI respondents

[Percent]

Disability:	
Paraplegic	36
Quadriplegic	11
Polio	10
MS	41
Sex:	
Male	97
Female	2.6
Use VA facilities:	
Yes	67
No	32
Marital status:	
Single	12.0
Married	68.0
Widowed	3.8
Separated	2.6
Divorced	13.0
Period of service:	
World War I	1
World War II	51
Korea	19
Vietnam	20
Peace	6
Compensation and pension:	
Service	64
Nonservice	35
Age:	
30	3.3
31–35	8.0
36–40	8.1
41–45	5–0
46–50	10.0
50 and over	64.0
Under 50	35.0

Initial findings from this effort, combined with other information PVA has received, indicates a need for improvement in certain areas of the VA SCI Program. For example PVA has a large concentration of members in the "Sunbelt States" and these states have special features which will attract additional SCI veterans in the future. The climate is attractive, to the SCI veteran because of the absence of restrictive winter conditions which exist in more northerly states. These veterans who must use wheelchairs for mobility are not house-bound, as often happens during snowstorms or during freezing weather conditions. This restriction in other areas occurs either because of an inability to use a wheelchair in such conditions or because of health dangers associated with spinal cord injury. Also, due to the large number of elderly residents, other features of accessiblity exist. Some efforts have been made in many areas of these states to provide for the unique needs of SCI vet-

erans and other disabled individuals. Transportation, employment, and recreation facilities are frequently available. These factors lead PVA to believe that a proportionate increase in SCI veterans can be expected to relocate to these areas.

The present large number, and the expected increase of SCI veterans in these areas, requires prompt action by the VA to provide for their health-care needs. For example, Florida is currently the second largest state in number of SCI veterans treated by the VA. There are currently two designated SCI Centers in the state, which are located at Tampa Veterans Administration Medical Center and Miami Veterans Administration Medical Center, both of which provide out-patient and in-patient care. PVA is especially concerned about the present and future capability of the SCI Center at Tampa VAMC to fulfill its assigned mission. This unit has 42 operating beds and is currently overutilized, according to VA SCI Service information. The unit now works at or within 1 bed of 100 percent occupancy on a daily basis. The unit is overcrowded and has a continuous waiting list for patient admission.

PVA understands that the same conditions also exist at the Palo Alto, California, and Houston, Texas, SCI Centers. VA reports for the period ending May 31, 1982, show an occupancy rate of 93 percent for Palo Alto and 100 percent for Houston. These figures represent an average daily census of 28 patients for 30 beds in Palo Alto, with a total of 52 individual veterans hospitalized during the month. At Houston the average daily census was 21 patients for 22 beds and a total of 29 SCI patients hospitalized.

This is especially significant for SCI patients who require continuous medical care, including regularly scheduled medical checkups, to ensure that problems are diagnosed before they become critical and possibly life-threatening. When emergency situations develop, as they continuously do with SCI patients, the overcrowding becomes especially crucial. Often, less seriously ill SCI patients must be moved out of the SCI unit to wards where the personnel are not experienced in dealing with the patients' special medical needs. And, emergency admissions mean that patients scheduled for admission must be abruptly notified of cancellation and re-scheduling. This can be especially frustrating for catastrophically disabled veterans who have special travel problems which must be arranged in advance. Also, the problem is further aggravated when SCI veterans must plan to travel long distances, as is often the case.

PVA believes the special needs of the aging SCI veteran must be addressed in planning for VA health-care delivery in the future. In the "PVA Response to Spinal Cord Injury Program Plan Fiscal Year 1980–1987," dated March 15, 1980, PVA noted that the VA proposed to expand the SCI service nation-wide from 18 centers with 1,386 beds to 23 locations with 1,565 beds. On a level-of-care breakdown this would provide 236 beds (15 percent) for intensive rehabilitation, 845 beds (54 percent) for sustaining care and 484 beds (31 percent) for long-term care. PVA concurred that an increase in SCI beds was required and PVA has supported an increase in the percentage of long-term care beds from approximately 25 percent of total SCI beds to the projected level of 31 percent of total beds. This support reflects PVA's realization that, as the SCI veteran population ages, the need for long-term care beds will increase. PVA now requests that the special needs of the aging SCI veteran be specifically included in planning for future VA facilities.

This request is specifically based on the concern for aging veterans that has been expressed by all veterans' service organizations, the Congress, members of the Administration, and our society in general. PVA is sure that all citizens concerned for the welfare of our aging veterans are aware of the questions raised in this area by Administrator Robert P. Nimmo and others. The questions of future funding of VA construction projects and the ability to provide the best possible health-care services to the aging veterans are closely related.

The initial information from the SCI Study shows a definite need for increasing the number of SCI beds. An example is the Dallas, Texas area. The Dallas VAMC reports the highest annual numbers of discharges for SCI patients. This facility is an SCI Center in everything but name. Yet, because of the lack of designation the SCI Center concept of treatment is not available. This situation obviously does not represent the provision of the best possible health care to those veterans who have incurred SCI. Especially absent is the specialized care required for the aging SCI veteran.

Those veterans who are now becoming the aging SCI patient are a new anomaly to the medical profession. These veterans with a specific, unique disability have no historical medical counterparts on which their course of treatment can be used as they age. The relationship of SCI medical problems to geriatrics and gerontology must receive immediate attention of the highest priority. The VA, as the largest

provider of SCI health care through a unified health-care system, should be immediately assigned this task.

PVA has identified some possible solutions to the problem of VA provision of high quality care to aging SCI veterans. Some of these solutions should be used by the VA in planning for future needs. PVA believes that the establishment of additional satellite clinics, which could be located outside the currently established maximum distance from VAMCs, should be adopted by the VA. These satellite clinics could possibly be co-located with Department of Defense installations or stations under the proposed VA-DOD Sharing Agreements, which are to be implemented. In instances such as this, the use of DOD-supplied resources such as space, medical diagnostic or treatment equipment, maintenance, and transportation could be utilized by teams of VA health-care personnel who would examine and treat the patients. Combinations of physicians, registered nurses, rehabilitation therapists, and others could provide traveling teams to visit designated locations at specific intervals. A number of these teams with emphasis on different medical specialties could travel a "circuit," visiting a different location on a scheduled basis. In this manner a satellite clinic could present care for aging veterans with a Geriatric's Specialty Team on one day, for heart patients with a Cardiac Specialty Team on another day, for SCI veterans with an SCI Specialty Team, and so on. This concept would be a cost-saving measure because the reimbursement for traveling long distances by each veteran which would be saved, combined with the use of DOD supplies, equipment, and facilities, would offset the small cost of transporting the VA Specialty Team to the different locations. PVA supports this concept and requests that the VA conduct further studies on its feasibility.

PVA believes an expansion of the Hospital Based Home Care program would significantly improve the VA's capability of delivering high quality care to aging veterans. PVA has a number of members who have utilized this program to improve their quality of living. PVA believes that every consideration should be given to placing eligible veterans in this program. Those veterans whose medical condition has stabilized, and who have the necessary family support to enter this program, should be encouraged to do so. The VA should also consider the possibility of additional cost-savings from a program such as this which removes the veteran from the VA hospital to his own home. Also, the establishment of satellite clinics may provide a possible method of expanding this program geographically.

PVA also supports extending the Fee Basis Home Health Care Program. This, again, is the type of VA program that is cost effective and provides quality health care to the veteran. PVA supports efforts such as this program in an attempt to provide the best possible health care to the largest number of veterans at the lowest cost. PVA believes programs such as this allow catastrophically disabled SCI veterans to maintain a viable home environment in the community. The result is greater personal satisfaction for the veteran and less cost to the VA and the taxpayer. PVA believes this program could serve as a prototype for the provision of services to a significant number of aging veterans.

PVA also requests that the VA consider expanding the range of services provided through programs such as Independent Living Centers, Congregate Housing, and Geriatric Day care. Each of these programs is a cost-effective method of dealing with special medical requirements of the patients involved. PVA believes that the VA must consider programs which might currently be outside the range of services or systems of delivery now used when planning for the future needs of aging SCI veterans. However, the VA SCI Center should be the focus where all of these programs are based. Any programs for aging SCI veterans should be under the supervision and control of those medical professionals who specialize in SCI care.

PVA has been informed of other problems with the VA health-care system and the services it provides to SCI veterans. A continuing problem is the recruitment and retention of trained nursing-care personnel. Due to the large number of elderly residents, the huge population, and the rapid increase in advance medical treatment available, all health-care facilities are continuously seeking qualified nurses. The ability of the private sector to provide higher pay, more comprehensive benefits, and flexible working hours adversely affects the VA's ability to recruit and retain nursing care personnel. PVA has addressed this topic in previous testimonies where we pointed out that this situation is especially harmful to the staffing of SCI wards.

Due to the medical condition of the patients, nurses are called upon to provide more intensive, time-consuming and rigorous care. PVA believes that the dedicated nursing care personnel who serve in SCI Centers should be compensated accordingly. Also, PVA hopes that the Chief Medical Director will quickly act to implement special incentives such as premium pay for Saturday work and use of the "weekend alternative," or Baylor Plan, in SCI Centers as soon as these additional recruiting

and retention aids become available. Another possible means of alleviating the nursing shortage in SCI Centers would be to designate a certain percentage of the available nursing scholarships to ensure that future nurses are trained in SCI health care and required to work a specific period in VA SCI Centers.

This problem also affects the physicians who staff SCI units. These are the individuals within the VA health-care system that must explain to a high level quadriplegic with symptoms of dangerous medical problems that no room exists in the SCI unit, or even in the hospital. Continuous exposure to this type of situation will adversely affect the VA health-care delivery system.

Concern also exists about the current ratio of health-care personnel to patients in SCI Centers. The May 31, 1982, Report of Spinal Cord Injury Centers indicates that of a total 2,202.5 FTEE's assigned, 474.8 are listed under the category "other." PVA requests that the VA provide a complete listing of exactly what jobs these individuals are performing and a comparison of the total number to that which other services must absorb. This information should assist in determining the exact number of additional nursing care personnel who should be assigned to SCI Centers.

The VA studies on aging veterans, coupled with the information from the SCI Report, lead to several conclusions. PVA believes the VA must act immedtiately to properly plan for, and implement, methods of dealing with the health-care needs of aging veterans. The methods chosen must be those that can be most easily implemented within reasonable cost constraint, and must be available when needed.

The information now available indicate the need for additional SCI beds and SCI Centers in the VA Hospital system. The indications of demographic changes presented in the VA studies on aging veterans and the SCI Registry Report must be considered by the VA in planning for future resources. PVA believes that there is an obvious need for SCI services throughout the VA health-care system. PVA, in previous testimony before the House Veterans' Affairs Committee, has supported the concept of basing future construction on demographic studies, if such studies are not used as an excuse to halt needed projects. The information on SCI veterans is available now.

PVA calls for immediate action by the VA to plan for and provide the needed resources for the SCI Service. This planning must consider not only the number of additional beds and SCI Centers that are required, but the appropriate mix of beds. The planning must specifically include a means of providing the correct number of beds in the right location for providing health-care services to aging SCI veterans. This requirement must be met by designating an appropriate number of beds for acute care for sustaining care, and for long-term care.

PVA is concerned that the VA Office of Construction's role in the planning process for additional beds has become distorted. PVA understands the restrictions imposed by fiscal constraint have impacted severely on the VA's construction plans. However, a dichotomy exists within the structure of the VA, where the Chief medical Director bases construction needs and timetables on the assessment of existing and future patient requirements, but, the Office of Construction bases construction needs and timetables predicted on existing and projected budget considerations.

The Administrator's interruption of the planned VA construction program has had a definite negative impact on the ability of the VA to provide health-care services to SCI patients. This impact has affected the SCI service nation-wide.

As stated, the need for additional sustaining care beds in the Sunbelt States is well known. yet the status of the construction program for areas such as Houston, Dallas, and Tampa is apparently undecided.

There also exists a well-known need for additional long-term care beds in the SCI Service. Major metropolitan areas such as Boston, Massachusetts, and Chicago, Illinois, have large numbers of elderly SCI patients. The present method of construction planning has failed to address their changing needs.

Mr. Chairman and Members of the Subcommittee, PVA is aware of several VA medical facilities where the health and medical care and the well-being of spinal cord injured veterans are being sacrificed because of the conflicting goals held by the Department of Medicine and Surgery and the VA Office of Construction. The most notable, and most urgent example, is Hines VA hospital in Chicago, Illinois.

There is a 160-bed acute care facility at Hines, but no long-term care facility exists. The VA's Department of Medicine and Surgery has long seen the need for a long-term SCI facility at Hines, and one continues to be listed in the VA's Five-Year Construction Plan; however, despite the Chief Medical Director's best efforts, no construction is expected in the near future, largely because the VA Administrator fails to agree that funding should be made available for such a facility.

The Chief Medical Director has consulted PVA for over two years concerning feasible alternatives to the construction of the needed 40-bed long-term facility: the al-

ternative is to bridge the gap which exists between urgent, current demands and the construction of a suitable facility. Despite this two-year effort, no adequate solution has been reached by the VA, largely because no alternative to specialized long-term care will meet the needs of SCI veterans.

There is this obvious conflict between the medical needs of veterans, as recognized by the Department of Medicine and Surgery, and the willingness of those in charge of construction to go forth with projects aimed at benefitting spinal cord injured veterans. The conflict is compounded, furthermore, because of other forces. It appears that long-term care SCI facilities are some of the most troublesome health-care services, in the minds of hospital administrators: aging SCI veterans present hospital administrators and health-care personnel with the problems of aging, but compounded by the complexities associated with spinal cord injury. Therefore, there is a desire to remove long-term SCI veterans from VA hospitals.

At Hines, the most recently proposed solution to the absence of a needed long-term care facility is to contract with nursing homes for the care of SCI veterans. This contracting is to supplement the inadequate VA system at Hines. It was decided unilaterally by those in charge of the Hines facility that sixteen (16) SCI veterans in need of long-term care would be sent on a contract basis to non-VA nursing homes. Others would be placed in the Hines VA nursing home, and still others would be dispersed throughout the existing acute-care SCI facility. (Last year, 18 such veterans were sent by Hines to non-VA nursing homes, and this year has already seen 12 placed in similar nursing homes.)

PVA recognizes several problems inherent in the Hines proposal: in the case of non-service-connected disabled SCI veterans, there is a statutory prohibition against contracting for more than 6 months, which means that the individual SCI veteran will be transferred to a nursing home, then back to the VA long enough to renew his eligibility for contracting care, and then out again to a nursing home. It is quite likely that by the time he is eligible to return to a non-VA nursing home, the original one will be filled and the veteran must then go to a different facility and be placed in the hands of personnel who are not familiar with him or with his SCI-related health-care problems.

Second, PVA remains fearful of nursing home care for SCI veterans (whether VA or non-VA) because of the results we have witnessed, as SCI veterans have returned for hospitalization after episodes in non-specialized nursing homes.

Care of SCI patients in general nursing homes as often as not ends in a worsening of the individual patient's condition for a number of reasons, and this deterioration creates a need for expensive medical treatment and causes needless suffering for the veteran.

General nursing home personnel are not trained to deal with SCI patients, and a noteworthy example of this is the incidence of decubitus ulcers, a life-threatening condition for SCI patients. Only experienced personnel can treat such patients without doing considerable harm to them, since circulation is greatly restricted and decubitus ulcers commonly arise from bed sores, bruises, and pressure sores. Non-specialized nursing homes do not have qualified, experienced personnel, and they are therefore unable to care adequately for the needs of SCI veterans. Health-care statistics support PVA's observations that non-specialized personnel are not able to recognize symptoms of decubitus ulcers, urinary tract infections, and other aliments common to SCI patients.

PVA has been told that SCI veterans at Hines will be sent only to "accessible" nursing homes, which is of little comfort to us: having a building with accessible bathrooms, for example, is not a substitute for having a facility whose personnel are trained to deal with SCI patients. Furthermore, there is no substitute for the concern and patience possessed by those who have chosen to make careers of dealing with spinal cord injured persons: nursing home personnel too often lack this willingness to work daily with persons whose conditions are as demanding as are those of SCI patients.

It is apparent that the situation at Hines flies in the face of both good management and of the VA's ability to care for severely disabled SCI veterans. Here, the VA has recognized the need for a long-term facility specializing in the needs of SCI veterans, the Chief Medical Director has worked to have this facility realized (or at least some workable alternative instituted), and yet SCI veterans in the Chicago area continue to receive inadequate care. Furthermore, those who are most in need of appropriate care, the ones whose health demands long-term care, are the ones who are about to be placed in the hands of inexperienced personnel.

It is also evident that the VA is unable to respond to the emergency situation which has arisen, either because Congress has made available restricted funding or because the Administration refuses to spend available monies for the care of needy

veterans. PVA fails to understand why the VA Administrator has failed to approve construction of the 40-bed long-term SCI facility at Hines, especially since health-care experts within the VA have long recognized the need for this project. We see clearly, however, a number of undesirable results coming from the lack of emphasis on caring for the needs, of SCI veterans, including a willingness by local hospital administrative personnel to use this as an opportunity to contract out for nursing home services and thereby not have to deal with the stringent demands of caring for SCI veterans who are in need of long-term care.

The VA SCI Service music rather than static. As stated above, the medical profession has never before had to provide the needs of an aging SCI population. There must be immediate action by the VA to start planning for such care so that the resources can be provided when and where needed. This planning must also ensure that the required number of nursing care personnel are provided in relation to the number and mix of beds.

PVA's present internal structure consists of four major Programs. We have an active Service Program dedicated to serving veterans, whether or not they are PVA members. Additionally, PVA, which is politically non-partisan, has a Legislative Program dedicated to monitoring the activities of Congress and the Administration, and an Advocacy Program which works to ensure proper implementation of federal and state laws dealing with the rights of disabled citizens. Finally, PVA has a Research Program of which we are especially proud. Annually it provides nearly half a million dollars for health research and health-care education projects. Funds to support this Program are raised and contributed by PVA. Through this Program, PVA and Stanford University, for example, created the nation's first Chair of Spinal Cord Injury Medicine, an educational pursuit which should benefit veterans and non-veterans alike.

The Veterans Administration's mandate for research and development, including specific efforts in spinal cord injury, is contained in the U.S. Code, Title 38, Section 4101c(1). The VA's Department of Medicine and Surgery is responsible for research and development (R.&D) programs. The fundamental strategy of the VA's health care system is to view research and patient care as an integrated whole with each component enhancing the quality of the other. The goal of this strategy is to develop and maintain the highest quality patient care system possible. Research and Development is comprised of three services: Medical Research; Health Services R&D; and Rehabilitation Engineering R&D. All three services conduct and support research within VA facilities and in cooperation with universities, medical schools, private organizations, and other federal agencies. VA physicians and other health professionals are encouraged to participate in research activities by seeking VA funds or funds from outside sources. More than 4,000 medical investigators were engaged in nearly 5,300 projects or programs at 119 of the 172 VA Medical Centers, at a total cost of $137.7 million in fiscal year 1980. All three services are involved with spinal cord research.

The Medical Research program's overall goal is to provide an excellent biomedical research program that improves the health care of veterans, by utilizing the unique features of the VA system. The Medical Research service consists of four funding programs. They are basic institutional research, high priority research, career development research, and the cooperative studies program.

The Basic Institutional Research program is research initiated by VA investigators. Funds are provide to investigators to pursue projects and subjects of their own choosing. This program is viewed as essential in attracting and retaining high quality medical personnel: in the 1981 Program Evaluation Report on the Medical Service, 75 percent of the physicians responding to the evaluation's survey indicated that the availability of research had a major impact on their recruitment. Also, of the respondents, 80 percent research as having an impact on their retention.

The High Priority Research program was instituted in fiscal year 1977 when Congress mandated VA efforts to identify the problems of the aging veteran. Congress intended that VA resources and facilities be focused on the medical care of aging veterans. The High Priority Research program is an example of a centralized research management program, as opposed to the investigator-initiated research embodied by Basic Institutional Research. Since its inception, the High Priority Research program has focused on other areas designated by the VA. In historical order, these areas have been aging, etiology of alcoholism, tissue regeneration, spinal cord injury, delayed stress disorders, and biological classification of chronic schizophrenia.

In its implementation of this program, the VA has utilized the concept of "centers of excellence." This approach funnels funds, personnel, and equipment to VA health facilities where the VA believes (based upon the number, quality and type of re-

search talent, patient population, and research history) that the prospects are excellent for the development of productive programs. The Regeneration Research Office at the VA Medical Center in Portland, Oregon is an example of a "center of excellence."

There is a second type of High Priority Research which is investigator-initiated, encouraged by Central Office Medical Research funds. This is "Special Emphasis Areas" research. Unlike the first type of High Priority Research, Special Emphasis Areas proposals are solicited for a general area and investigators initiate their own approach and expectations. The areas are selected on the basis of importance to the veteran population without any special reserve of funding. Proposals for Special Emphasis Areas must compete with all other proposals for Basic Institutional research because this is its source of funding.

The High Priority research for SCI regeneration began in fiscal year 1980. Career Development programs provide a period of concentrated research for the VA's most productive and/or promising clinical investigators. This program, as with all research within the VA, is available not only to physicians, but also to other health care professionals who are interested in obtaining research support. The Career Development Program has five levels which basically parallel the succeeding steps in academic medicine for a clinician's career. The five steps are associate investigator, research associate, clinical investigator, medical investigator and senior medical investigator. Each level is awarded complete in itself. Program participants are selected through the VA's merit review process.

The Cooperative Studies program involves investigators from two or more health care facilities who volunteer to study cooperatively a selected medical problem in a uniform manner, under common protocol, and with central coordination. Cooperatives studies generally are directed towards "clinical trials," i.e. evaluation of treatment modalities. Studies continue for 3 to 5 years so that longevity factors are assessed. Studies in this program tend to be the most expensive, with a typical study costing about $1.5 million. Cooperative studies permit researchers to collect large amounts of data from a broad geographic area. Areas for cooperative studies have included treatment of hypertension, schizophrenia, diabetes, alcoholism, heart disease, and epilepsy. Currently there is a cooperative study of SCI individuals that is focusing on kidney stone treatments.

The Office of Regeneration Research Programs was established in 1980, as a focal point within the VA for central nervous system (CNS) regeneration research programs. The office is located at the VA Medical Center in Portland, Oregon. The Regeneration Research Office performs two functions for the VA's Research and Development Office (R&D) of the Department of Medicine and Surgery. First, the Director is a consultant to the Merit Review Programs within R&D on regeneration proposals. Second, the Regeneration Office is a clearinghouse for information on regeneration research projects and on funding resources within and outside the VA.

VA regeneration research is defined as the study of the mechanisms for repair and regrowth of the injured central nervous system; reorganization of the CNS; and, regeneration of non-nerve tissues such as muscles, affected by CNS injuries. The VA's regeneration research projects focus on the entire central nervous system, i.e. brain tissue, spinal cord, and peripheral nerves. In this regard, regeneration research for the Veterans Administration and the National Institute of Neurological and Communicative Disorders and Stoke is identical. Knowledge gained in each area contributes to the understanding of the entire CNS. The three principal elements of the central nervous system are unique to themselves, yet their interrelatedness is too significant to isolate them from each other. It must be stressed that the VA's fiscal expenditures for regeneration research in each area need not be equal to demonstrate the Administration's commitment. Rather, the VA's commitment is represented by the total expenditures for regeneration research and the existence of this office.

The Program's primary focus favors basic scientific investigations over clinically-oriented research, because that is the current status of CNS regeneration. Prior to 1970 the scientific conviction of most investigators of CNS ailments was that regeneration was not a plausible pursuit. The world scientific community had resigned itself to this conviction so strongly that no efforts were being made to prove or disprove it. Therefore, it was not surprising that no reserach results existed to challenge this conviction. Scientists knew that CNS regeneration was possible for certain non-mammalian species. Scientists also could reconnect/relocate peripheral nerves in mammals, but the process was very risky in 1970. However, around 1970 researchers throughout the world began to question seriously the traditional conviction. Today, the concept of CNS regeneration is all but assured as science learns more of the physiology, functions, and relations of the CNS parts.

One significant activity sponsored by the Regeneration Research Office during its first year of operations was a symposium/workshop in the fall of 1981. This symposium involved 19 investigators from a the VA and university affiliated programs discussing the "state-of-the-art" relative to CNS regeneration research.

Individual research papers were distributed at the symposium, in addition to the general conversations among investigators. The symposium was a success and a second one is scheduled for September 1982. The format will be consistent with last year's symposium. However, this year's proceedings will be published.

The Regeneration Research Office does not disburse research funds. The VA apparently intended to spend approximately $1 million for regeneration research projects in fiscal year 1981. However, anticipated budget cuts resulting from the Reconciliation Act of 1981 reduced this earlier estimate. The specific effects of budget cuts are uncertain at this time, but three problems are foreseen. First, there is the loss of some current projects. Second, is the reluctance of project reviewers to entertain innovative proposals. The third problem is the increased pressure placed upon outside funding resources.

A final goal of this office is to increase the awareness of decision-makers and the public concerning the need for the regeneration research. This need to create better awareness is made clear by the cuts in budgets. Perhaps there is no way to avoid budget cuts, but their severity might be reduced if decision-makers were more sensitive to research activities and value.

As stated, PVA has historically supported the goal of finding a cure for SCI. However, non-profit groups such as PVA cannot carry the burden of supporting the necessary efforts in SCI research. There exists a need for government funding and coordination of research in this area. The past two fiscal year budget proposals have reduced funding for all VA research activities. This reduction has had a deleterious effect on SCI research. PVA is particularly concerned that this reduced funding is representative of more than just fiscal restraint—we fear that it is a statement that spinal cord injury does not warrant society's serious consideration. Hopefully, though, Congress will renew its efforts to ensure that medical research receives sufficient funding. And, PVA trusts that until a cure for SCI is discovered, the Congress will continue to provide adequately for the existing needs of SCI veterans.

Mr. Chairman, this concludes my statement and I will be glad to answer any questions that I can.

STATEMENT OF D. EARL BROWN, JR., M.D., ASSOCIATE DEPUTY CHIEF MEDICAL DIRECTOR, DEPARTMENT OF MEDICINE AND SURGERY, VETERANS' ADMINISTRATION

Mr. Chairman and Members of the Subcommittee: I am pleased to have the opportunity to discuss the Veterans Administration's Spinal Cord Injury Program.

The VA has played a pioneer role in the management of the spinal cord injured since World War II.

Spinal Cord Injury (SCI) is a disability primarily afflicting young men. It is a disability which almost invariably had an early fatal outcome, upon which the medical profession reported only randomly in the past, and, with uniform pessimism, until World War II. The war that ended in 1945 coincided with the discovery of the sulfonamides and the antibiotics. This changed the life expectancy of the spinal cord injured dramitically, and most of the 2,000 American combat casualties with this type of disability survived.

The Veterans Administration assumed the care and treatment of the SCI patients whom military hospitals had gathered in special centers. Thus began a unique medical specialty which the Agency has continued, building a service that now manages 19 Spinal Cord Injury Centers.

In its beginning, the VA treatment program established some large centers: Long Beach, Hines (Chicago), Memphis, West Roxbury, Bronx and Richmond. With the gradual buildup of the patient populaion over the ensuing 35 years, the VA expanded this service by creating additional, smaller units, now totaling 19, with more than 1,300 total SCI beds.

Ten percent of the nation's living veterans use the Veterans Administration for their health care needs. By contrast, 75 percent of veterans who are spinal cord injured use the VA for their health care needs. This is due to the availability of special skills at the VA centers no less than to the expensive nature of this catastrophic disability. Prolonged hospitalization and a variety of recurring complaints contribute to make this disabiltiy an unusually expensive one. A recent study covering program experience between 1976 and 1981 reveals that VA medical centers treated more than 16,000 individual spinal cord injured veterans. This number included approximately 900 new patients a year and, of these, nearly half represented new inju-

ries requiring more intensive rehabilitation. Our demographic survey currently in progress shows that California has the largest population of SCI veterans with Florida, Texas, and Massachusetts following in that order.

VA SCI Centers provide a full range of medical and rehabilitation services managed by a multidisciplinary team of professionals headed by a physician and including registered nurses and other nursing personnel, social workers, psychologists, physical medicine and rehabiliation therapists.

A full course of rehabilitation leading to discharge to the community is the fundamental mission of the program which is usually achieved in four to six months. The bulk of services provided by the SCI Centers is the lifetime health maintenance for these veterans through periodic checkups and acute treatment of the many life-threatening complications to which they are susceptible. The insitutationalization of the SCI patients, for whom no community placement is possible, such as the elderly quadriplegic with minimal financial and family resources, is also the concern of the VA addressed through its spinal cord injury long-term care program.

THE INJURY

Unequivocally, spinal cord injury causes a catastrophic disability with an incidence of 3 per 100,000 in the general population per year. There are 150,000 spinal cord injured individuals in the United States.

In peacetime, the most common cause of spinal cord injury is the vehicular accident (50 percent). The mechansim is usually a violent flexion, extension or rotation of the body which causes a fracture or fracture-dislocation of the spine. This, in turn, damages the spinal cord which is contained within a canal in the spine.

Inasmuch as the cord, which is part of the central nervous system, does not grow back (regenerate), permanent loss of function below the injury is the rule. When the level of the injury is below the neck, a paralysis of the lower extremities occurs and is called paraplegia. If the injury is in the neck (50 percent), some paralysis of the arms occurs as well and is called quadriplegia. In all cases, loss of control of the bladder and rectal junction also occurs. Sexual function is also impaired, both functionally and reproductively.

In addition, these patients are prone to serious, incapacitating complications, such as urinary infections, pressure sores, and pneumonia, all so which often require repeated hospitalizations, sometimes for long periods. Though vastly improved, the life expectancy of the spinal cord injured depends upon the severity of the injury—the more severe the injury, the shorter is the life expectancy.

MEDICAL MANAGEMENT

The intial handling of a newly spinal cord injured individual at the accident site is of paramount importance with respect to such factors as immobilization, preservation of the airway, and control of shock. Fortunately, this special handling has improved dramatically in this country with the training of paramedical personnel and with the disemination of basic information on first aid and cardiopulmonary resuscitation to the general public. This has probably resulted in large measure in preservation of life and improved function for SCI victims.

It is vital that the hospital where the patient is first taken has adequate access to medical specialties such as neurosurgery, orthopedics, and urology, to ensure that these patients are cared for appropriately. An early transfer to an SCI Center is desirable, but must be delayed until the patient's condition is stable enough to permit safe transport.

The initial management of the injury, after a thorough physical and X-ray examination of the patient, consists of immobilization in a frame or the application of traction in neck fractures. About half of the these patients require spinal surgery to secure reduction and decompression as well as immobilization.

Intermittent bladder drainage by cathether and range of motion therapy, as well as scrupulous and assiduous nursing care to prevent pressure sores and maintain nutrition, are part of the early care of the SCI patient. Psychological and family support and involvement are indispensable. A rehabilitation plan is developed in concert with patient and family.

REHABILITATION

Social and psychological problems associated with SCI require massive readjustments, and, in the process of trying to adapt to these, the SCI patient experiences emotional reactions of anger, depression, guilt, resistance and dependency—all of which must be worked through before rehabilitation can be accomplished. Other up-

setting obstacles to living with this disability are architectural barriers such as stairways, curbs, narrow doorways, and inaccesssible public transportation. How effectively the individual is able to cope with these difficulties is in large measure dependent upon the internal resources and assets of the patient. It is the role of the SCI multidisciplinary staff to help the patient find the programs and services needed to deal effectively with this situation and to call upon the substantial psychological reserve and strength required during the rehabilitation process.

The VA's program's goal of rehabilitation is to return the SCI veteran to the mainstream of society with the attitudes, skills, assistive devices and equipment necessary to function as independently as possible in physical, social and vocational areas. The expected outcome of treatment of a new injury is that after medical stability is reached the patient will be able to complete a program of comprehensive and intensive rehabilitation is a period of four to six months post injury.

Most SCI veterans achieve a successful therapeutic rehabilitation. Eighty-five percent of SCI discharges are to the patient's own home. Approximately SIC percent of SCI patients are discharged to nursing home programs in the VA or to the community. The remaining patients go to other private sector facilities.

Rehabilitation of the SCI patient in the vocational area has been less successful for a number of reasons. A comparative study of employment of SCI patients (one-year post-injury) conducted in 1979 showed that rates of employment of patients in VA Spinal Cord Injury centers and patients in the National Spinal Cord Injury Data Research Center were very similar. Twelve-point-two percent of the VA patients were employed, compared to eleven-point-three percent of the National SCI Data Research patient population. Factors associate with successful vocational rehabilitation efforts are: age at injury, level of injury, employment status (pre-injury), marital status, and vocational skills possessed. A complicating factor, particularly for the veteran who is nonservice-connected, is the disincentive to achieve gainful employment. This achievement now results in a loss of VA pension, social security, and, in some cases, a loss of aid-and-attendance benefits. It has been estimated that because of the regular ongoing costs of living with a spinal cord injury, a patient must earn in excess of $20,000 a year to compensate for the loss of these benefits.

Advances in the physical rehabilitation of the SCI patient and the provision of appropriate assistive devices and mobility aids have progressed rapidly in recent years. These advances tend to outstrip the patient's capacity to make necessary psychological adjustments to altered physical states and physical limitations.

An important element in the rehabilitation process is the stimulation of the patient to think in terms of life goals and ambitions and to strengthen the capacity for realistic assessment and decision-making. Patient education programs focus on teaching patients to understand and care for the disability and to assume increasing responsibility for health maintenance activities. Formal programs in bladder management, skin care, bowel care and intermittent self-catherization are conducted by nursing service staff in all SCI Centers.

For more severely disabled patients who are unable to care for their own personal needs, an attendant is required. The attendant may be a family member or an employee who must be trained in patient care and nursing procedures. Most SCI Centers have home environment clinics where family members or attendants can be trained in a homelike setting in such tasks as dressing and bathing, trasfers from bed to wheelchair or commode, irrigation of catheters, examination of the skin, and turning at regular intervals to prevent bedsores.

When a patient lives within a 50–60 mile radius from the medical center, family training started in the home environment is continued in that environment by the SCI Home Care Team until the patient and family are proficient in home health care management.

Special attention is given to providing the patient with needed supports to function both within the home and the community. This includes wheelchair prescription and design and VA assistance in obtaining structural alterations to the home to accommodate this equipment. For the service-connected SCI veteran, grants can be authorized for specially adaptive housing. Automotive adaptive and drivers training equipment is also made available so that the patient is able to travel independently of others. Special electric wheelchairs which can be operated by mouth controls are provided to veterans who do not have full use of upper extremities. Environmental control systems which enable a quadriplegic patient to turn on a television or appliance, dial a telephone, call for help, open doors, turn pages in a book, etc., are also provided. Electric beds with special mattresses reduce the incidence of bedsores for quadriplegic patients, as do special wheelchair cushions.

Total rehabilitation is a re-socialization process. Since SCI is typically a condition of young men, the injury has often interrupted a normal maturation process and

permanently changed the victim's life goals and expectations. Many have not yet assumed adult roles such as marriage or career selection and must learn the social skills necessary to relate constructively to people. This process involves dealing with stigmatizing attitudes of society toward the physically handicapped. Help with these problems is often offered by other patients and their "significant others" in the handicapped community. Such assistance is referred to as peer counseling and/or consumer advocacy. It is important to emphasize that the successful rehabilitation of these patients is as much dependent upon social supports and attitudes as are the adjustments to loss of function created by the disability. The severely handicapped must learn to deal successfully with the non-disabled persons in life, to diminish the effects of the public's perception of limited-function potential and to become assertive when confronted with feelings of isolation or rejection.

Until recently the main alternative to hospitalization for the high-level injured or quadriplegic patient with no home to return to was a nursing home. This has not been the optimal placement. A more desirable option has arisen with the development of independent living programs. These programs permit many patients to live at home with the assistance of full or part-time personal attendants. There are approximately 130 independent living programs approved by the National Rehabilitation Services Administration, and some of these offer transitional housing where the patient can reside pending the location of an apartment and an attendant.

The program which has made the greatest contribution to the successful care of the SCI veteran in the community is SCI home care. Whenever possible, an SCI patient is placed in this program following initial discharge. Under home care the patient and family are supervised and directed in the patient's care and treatment until they can manage without assistance. Sixteen VA SCI Centers now have full or partially-funded home care teams. For the first half of this fiscal year, the SCI Home Care Program staffs have followed 660 patients and provided a total of 31,342 patient days of care.

A considerable amount of the SCI veterans' medical care is being furnished by VA medical centers which do not have SCI Centers. Social Work Services in VA medical centers without SCI Centers screen all SCI patients applying for inpatient or outpatient care to provide appropriate counseling, referral services, and informational materials, to insure that all SCI veterans receive appropriate care.

PROGRAM ADMINISTRATION

As a result of a 1977 National Academy of Sciences' recommendation that SCI patients be separated into two treatment groups: those who are likely to be rehabilitated and returned to the community; and, those who are likely to remain hospitalized for a long period. The VA has adopted three levels of SCI care and allocates resources accordingly. These levels of care are:

Intensive rehabilitation comprising individuals injured recently who require a full program of early medical management and rehabilitation leading to discharge to the community;

Sustaining care which comprises those patients who return to the hospital periodically for checkups or for the treatment of complications (this level of care accounts for the largest number of hospital days of care); and,

Long-term care which refers to those who have very limited fiscal and/or family resources and who also have a high degree of disability by being quadriplegic or aged. These patients frequently have some other serious physical infirmities which require close medical supervision.

Of the 19 VA Spinal Cord Injury Centers, the majority are in the East and Southeast regions of the United States. Large centers are being reduced in size and smaller centers established in areas where there is a need for such services. This is because we have learned that smaller centers are simpler to manage, provide more personalized care, and, with proper geographic placement, reduce travel time and costs to patients and their families.

The workload for the existing 19 centers is relatively constant. A typical year, 1981, is compared with the 5-year average, as follows:

	1981	5-year average
Operating beds	1,337	1,365
Average daily census	1,050	1,106
Turnover rate (percent)	46	42
Occupancy rate (percent)	79	81
Admissions	5,768	5,610

	1981	5-year average
Patients treated	6,890	6,773
Outpatient visits	33,849	31,704

The SCI program has an average of 967 "first-time admissions to the VA" a year, with 456 admissions being within the first six months of injury. These patients, consequently, are considered acute or intensive rehabilitation cases.

Newly-established SCI Centers were originally funded to support a staffing ratio of two-staff-to-one-patient (2/1). This allocation was based on a projected 95 percent occupancy rate. A 60-bed SCI Unit, for example, would be staffed with 114 people. This ratio was developed for "hands-on" or "direct patient care" staff and did not not include administrative and other support personnel.

The staffing for fiscal year 1981 is typical of the previous five years, as follows:

Average daily census (at 79 percent occupancy)	1,050
Full-time employee equivalent	2,210
Staff/patient ratio	2.1/1
Physicians	129
Registered nurses	400
Nursing assistants/licensed practical nurses	873
All other	808

STAFF EDUCATION

SCI Services provide continuing education for medical and other allied health staff to upgrade skills and help staff keep abreast of advances in technology and clinical management of the patient. Education programs in fiscal year 1981 addressed "spasticity and spasms" and "independent living." The topics in fiscal year 1982 covered the "care of the respirator-dependent patient" and "management of the disturbed and-or violent SCI patient." A session for a genito-urinary (GU) update for SCI patients is scheduled for fiscal year 1983.

Through the Office of Academic Affairs, a fellowship for physicians was started two years ago. It is two-year program designed to develop skills in the multidisciplinary care of SCI patients for physicians who already have a background in related specialties (neurology, orthopedics, urology, physical medicine, etc.). These fellows are assigned for a two-year period to one of five selected centers: Long Beach, Palo Alto, West Roxbury, Wood and Richmond. Currently there are 17 such physician-fellows in training: eight first-year and nine second-year. This year, five physicians were graduated, most of whom have been employed by existing centers. This is a unique training program which, in addition to disseminating skills, will provide a manpower pool to fill vacancies whenever they occur.

A Spinal Cord Injury Nurse Practitioner Program was also initiated. Under this program the VA and the Eastern Paralyzed Veterans Association jointly provided a 4-month concentrated course for qualified nurses who were given the opportunity to prepare themselves to give primary and long-term care to SCI patients. Twenty-seven nurses completed the program.

PLANNING SURVEY

Since January 1982, the Spinal Cord Injury Service has been gathering data concerning the SCI patient from the patient treatment file (PTF).

A collection of 5 years of retrospective data has identified 16,277 individual patients representing every state in the Union as well as the Virgin Islands, Puerto Rico and Guam.

In addition, it has possible to pinpoint areas where there are small concentrations of SCI patients using VA facilities that do not have centers. While it is not practical to establish centers where there are small numbers of SCI patients, we are planning to monitor the care of those patients from the nearest SCI center. The costs of Spinal Cord Injury Center care and the per dim costs have continued to escalate as have health care costs in general.

VA's direct medical "hands-on" care costs for SCI for 1981 was a little over $53 million and total operating costs, a little over $67 million. This translates to an average per diem cost of $216, a figure that is not likely to be replicated in any non-federal medical center.

RESEARCH IN SPINAL CORD INJURY AND REGENERATION

Research on spinal cord injury and regeneration is one of the VA's Office of Research and Development's high priority areas because of the severe disability and the long-term duration of illness and life support systems required by patients with spinal cord injury. As a high priority area, projects which are of high scientific quality receive full funding. In fiscal year 1981 the VA funded 168 such projects for a total cost of $2.5 million.

VA research programs address a wide array of problems. There are the urgent problems of acute spinal cord injury which are being investigated to determine how to limit the functional loss resulting from spinal cord injury and to prevent the sequence of events leading to further damage which may become irreversible. There are the practical everyday problems requiring solutions to improve the quality of life of spinal cord injured patients. Another area which offers the most promise for the future is research directed to stimulate the orderly regrowth, or regeneration, of nerves in areas of spinal cord damage. In spite of much research in this area, no one has yet been able to accomplish regeneration of nerves in the human spinal cord.

VA research programs to improve the quality of life of spinal cord injured patients are an integral part of an overall rehabilitation program. By applying the best technology, improvement can be realized in five areas. Systems are developed to assist the handicapped in the activities of daily living such as eating, shaving, answering the telephone, and reading a book. To improve the mobility of patients much effort has gone into the search for a better wheelchair and into the problem of prevention and cure of pressure sores. The development of manipulative devices and their control systems offer the handicapped the possibility of gainful employment. To avoid a life of isolation and confinement, travel with automotive adaptive equipment and enhanced recreational devices have been developed. During fiscal year 1981 funding for 19 such research projects was $1.1 million.

In the difficult area of spinal cord regeneration, the VA supports a dozen programs at the level of $706,000 in fiscal year 1982. These projects are investigating the regeneration problem by asking questions as to what factors stimulate the growth of nerves, what conditions are required from molecular, biochemical, immunologic, and physiologic considerations for nerve regeneration to occur, and what factors, such as the special scar which forms in the injured spinal cord, may interfere with regeneration.

In order to develop targeted programs and to attract talented investigators to regeneration research, the VA held a planning workshop on March 7, 1980. The result was the establishment of an Office of Regeneration Research at the VAMC Portland, under the direction of Frederick J. Seil, M.D., on July 1, 1981. The function of this office is the promotion of quality research in tissue regeneration. The goals include the development of a central file to monitor progress of regeneration research within the VA and to correlate VA research with those outside of the VA, to facilitate communication among VA scientists involved in regeneration research, to promote training in regeneration research, and, to work with representatives of other funding agencies to develop joint funding for combined proposals. Behind these goals are the aims to limit the barriers between basic and clinical research and to allow new, unique, and novel research required in the difficult area of regeneration of spinal cord. It is noted that the first newsletter entitled Regeneration Research Bulletin summarizing current work has been submitted for publication.

That concludes my statement, Mr. Chairman. I will be pleased to answer any questions you or members of the committee may have.

TESTIMONY OF LOUISE MCKNEW—NATIONAL SPINAL CORD INJURY ASSOCIATION

Mr. Chairman, distinguished members of this committee—I am deeply grateful for this opportunity to share my views on spinal cord injury with you.

Know in advance that I am not a veteran, and I am not here to comment on specific V.A. programs. I come before you as a taxpayer who helps foot the general bill for government programs and as an officer of the National Spinal Cord Injury Association (NSCIA), the only non-veteran membership organization dedicated to the care and cure of those with a spinal cord injury. I also come as an enforced expert on spinal cord injury; my son was injured in an accident over four years ago and remains paralyzed from the chest down.

Spinal cord injuries are indeed a V.A. issue—the Vietnam War alone sent 7,000 young men and women home in wheelchairs. But there's more—this is a national issue, an emergency about which most people remain dangerously ignorant:

In the next 24 hours, spinal cord injuries will paralyze another 60 Americans.

Over 20,000 people in this country are paralyzed each year, more than once were paralyzed by polio.[1]

We have estimated that 500,000 Americans are now spinal cord injured, but a recent California study permits a reasonable inference that the total national figure may be as high as 1.5 million.[2]

Most of the newly injured are young men—the average age is 19. Motor vehicle accidents account for almost half of the paralyzed population, but any accident which can break a bone—leg, arm, nose—can do the same to a neck or back. People fall out of trees, off ladders, and in the bathtub. Sports accidents claim blameless, innocent, athletic young people whose normal sense of adventure and exploding physical capabilities are indiscriminately challenged.

This is not a disease—you can't catch it. And it's not something you're born with or inherit. It just happens. This is not the time or place to identify the personal devastation wrought by a spinal cord injury, but you should know it's more than just being stuck in a wheelchair. It's an on-going, life-threatening, painful trauma, an insatiable consumer of energy, time and psychological resources. The emotional hurt is relentless—and it gets harder, not easier.

On a case by case basis it is the single most expensive medical problem in the United States today. I speak from experience:

Were my son to spend the rest of his life paralyzed, it would cost anywhere from $1 to $5 million. His initial hospitalization averaged $1,000 a day, the rehabilitation hospital cost $7,000 a month, the surgeon's fee for his first operation cost $2,500—and the expenses continue:

A modified van which he drives cost $25,000.

The house addition and modification cost $30,000.

Aides total $9,000 a year.

Physical therapy is $54 an hour.

Leg bags are $128 each.

Wheelchair batteries cost $84 each. And that's just a sample!

Medical deductions filed with my income tax for 1978, the year he spent in the hospital, total $14,872. These were expenses not covered by high option Blue Cross-Blue Shield insurance. This past year they were $24,226. Thi indirect costs are also high: Yale University invested over $170,000 in architectural modifications for Donny's freshman year—he was their first undergraduate to come in a wheelchair. The total continues to climb, and so does my debt.

On a national basis, the costs are proportionately staggering: the annual cost to the U.S. Government for the support and care of spinal cord injured persons, including Veterans, is approximately $3 billion—that's the government's contribution. Private dollars add another estimated $3 billion.[3] $6 billion a year—enough to fund 150 B1B bombers or one CVN nuclear carrier.

What are we getting in return for this massive, reactive response to spinal cord injury? In the acute stage, patients sometimes receive adequate care, often suffer destructive care, and rarely enjoy state of the art care. It has been officially admitted that less than 15 percent of the newly injured receive appropriate, immediate, and quality medical attention. Despite the existence of shock/trauma facilities, patients end up in local, private, or community hospitals, ill-equipped to deliver state of the art treatment. Too many medical specialists and support personnel are even aware of their ignorance and inadequacies. The results and prognosis for patients whose immediate care is mismanaged can be catastrophic—physically, psychologically and financially. The first few hours are critical and shortly will become even more so.

The rehabilitation picture isn't much better. There are some facilities, like the V.A. hospital outside Boston, where exemplary, ground-breaking work is on-going, where people use creative technology, first-rate training and genuine, loving con-

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[1] According to the Center for Disease Control, polio paralyzed 21,000 people in 1952, its worst year.

[2] In 1980, NIH estimated that spinal cord injuries paralyzed 10,000 Americans a year, and that 150,000 constituted the total population. Both figures were admitted to be "best guesses." A state of Pennsylvania study, an actual count, set the incidence rate at 90 persons per million, which translates to over 20,000 per year, nationwide. If 20,000 were paralyzed annually, a total of 500,000 would have been paralyzed in the last 25 years alone. NSCIA has used the conservative 500,000 figure until a better one can be documented. The referenced California study was prepared for the State Department of Rehabilitation in cooperation with the University of California at Berkeley and Los Angeles.

[3] Testimony before the U.S. Congress, July 22, 1980. "Spinal Cord Regeneration," hearing on H.R. 4358, Committee on Interstate and Foreign Commerce, Subcommittee on Health and the Environment.

cern to return an injured person to a useful independent life. But they are few and far between—thousands of people needlessly waste away in rehabilitation halls, or return home to empty rooms, absent families, and careless medical attention. Some die there. It's a personal tragedy and a national disgrace.

But let me tell you a secret. There is nothing hopeless, incurable or forever about spinal cord paralysis. What's more, we are on the verge of preventing paralysis as a result of spinal cord injury.

Despite the paucity of funds, despite the admonitions that paralysis is permanent, despite the lessons they learned in medical and graduate school, researchers have reversed the prognosis for spinal cord injury—they now predict cure. Transplant techniques, genetic engineering, biochemical and neurophysiological discoveries offer unpecedented promise for not only modifying, but preventing and curing the paralysis that follows a spinal cord injury.

Contrary to popular belief, most cords are not severed, they are bruised. Swelling, bleeding, and loss of oxygen to the cord are causes of paralysis, *not* the initial injury. Immediate care (2-4-6 hours) is critical.

Here at the Uniformed Health Services University in Bethesda one neurologist has already proved that paralysis is preventable in mammals. He is now setting standards for human clinical trials which will begin shortly.

In Canada, another clinician has been administering cooling techniques to the newly injured, preventing swelling from choking the cord's tender nerve fibers. The results are exceptionally encouraging. And there are others:

We are on the immediate threshold of permitting thousands to escape the devastating consequences of a spinal cord injury—the treatment, however, must be directed by experts and done so within the first few hours.

For those who now live with paralysis, there is extraordinary and well-grounded hope: lots of it!

We now know that the human spinal cord is capable of regeneration and that restoration of function to paralyzed muscles is possible.

Researchers are now grafting short pieces of healthy nerve tissue across injured sections of experimental injuries, bridging or bi-passing the bruised portion of the cord.

Other researchers are implanting nerve tissue and literally transplanting segments of nerves—if we can transplant kidneys, livers, hearts, even the entire heart/lung complex, why not a piece of nerve for the spinal cord?

Non-invasive chemical and pharamceutical substances are reportedly permitting long-paralyzed individuals to feel, to sweat, and in some cases to move for the first time in years.

Bioelectronics, an increasingly familiar term, combines our knowledge of biological processes with advanced electronic technology:

Using biofeedback techniques, one researcher is electronically identifying enervated muscles, ones previously diagnosed as hopeless. Functions have been restored to the point where two young people are now walking.

Another research scientist is picking up the brain's signals above the injury, via computer, interrupting messages to the legs and reinterpreting them for the responsible muscles—his paralyzed kids are peddling bicycles, and he hopes to have them walking within weeks!

Of special relevant to these hearings, you should know that Dr. Bernstein, at the V.A. research lab here in Washington, has offered extraordinary hope by applying the lessons of genetic engineering to transplant techniques. He can speak for himself, but I will tell you that the embryonic nerve cells which he implanted in an adult mammal are growing!

So you see, the problem has its promise.

Using the conservative figure of 500,000 persons now paralyzed by spinal cord injury, the $6 billion annual cost to the nation for care, and an overly generous estimate that we invest $16 million [4] in regeneration/restoration research, we find we are spending annually approximately $12,000 per person for care, and less than $32 per person for cure. That's fiscal insanity. The lopsided ratio of 400 to 1 becomes all the more skewed in light of the fact that with relatively little money, we can reduce the $6 billion national figure, substantially and soon.

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[4] NIH estimates its budget for "regeneration research" to be approximately $11 million. If the V.A. spends $2 million, and if the Department of Defense spends $2 million, and if the Paralyzed Veterans of America, the National Spinal Cord Injury Association and other private groups contribute $1 million, the total comes to $16 million. But the amounts are neither firm nor substantiated.

Last year the Pentagon was given $20 million to modernize its nerve gas facilities. For $30 million more, this year's program calls for the production of new lethal weapons that attack and paralyze the body's central nervous system. For an additional $55 million, the Army intends to produce 18,000 defensive anti-nerve gas kits that can't discriminate between truck exhaust and combat gas—over $3,000 for one useless kit.

Something is very wrong when it becomes more important to perfect our ability to paralyze people, deliberately, than it is to fund promising research that will unparalyze them.

I hope you will reconsider the V.A.'s investment priorities. Promising theories have yet to be tested, new discoveries have not been applied, and clinical trials have been further delayed because of inadequate funds. I ask you, as public trustees, to acknowledge the physical and fiscal benefits that will accrue to us all, veterans and non-veterans, if you aggressively commit to a cure.

Spinal cord injuries present a catastrophic, national threat of epidemic proportions—what happened to my son could have happened to yours. But research now offers the guarantee that he will walk. You, honorable gentlemen, have the power to accelerate his cure. It is no longer a question of if, but when!

Thank you.

MEDICAL COLLEGE OF VIRGINIA ASSOCIATED PHYSICIANS,
DEPARTMENT OF SURGERY, DIVISION OF PLASTIC SURGERY,
Richmond, Va., July 28, 1982.

To: Committee on Veterans' Affairs.
From: I. Kelman Cohen, M.D.
Re: Report of I. Kelman Cohen, M.D.

I. Personal background.—I am Board Certified in both General and Plastic Surgery and obtained my expertise in wound healing at The National Institutes of Health where I worked from 1970–1972 under an NIH Training Grant—funds allocated by Congress. Since 1972 I have served as Professor of Surgery and Chairman of the Division of Plastic and Reconstructive Surgery at the Medical College of Virginia and its affiliated hospitals which includes the McGuire Veterans' Hospital and have a deep interest in spinal cord injury (SCI) patients on both a clinical and research level.

II. Research.—In 1982 we have the methodology and creativity to significantly reduce the cost of SCI clinical care in several areas. Those which have sparked my interest include:

A. Reverse the Effects of Spinal Cord Damage in the Acutely Injured Patients: insignificant spinal cord trauma frequently results in complete loss of function below the area of cord injury. This can be prevented by research.

(1) Pharmacologic Control: recently, investigators have shown dramatic reversal of the effects of SCI using thyroid growth stimulating factor or endorphin (naturally occurring substances similar to narcotics) antagonists such as Nalaxone. It is not exaggerating to state that the paramedic who is the first to reach you after your auto accident may be able to inject you with the "magic bullett" which will prevent spinal cord paralysis and keep you walking rather than subject you to a life in a wheelchair.

(2) Regeneration: rather than healing by scar, perhaps the spinal cord can regenerate. The spinal cord is like a vast electrical circuitry. When cut, the ends get blocked with a material called collagen. This is the most abundant protein in the body and essential for healing everywhere but the nervous system. The electrical conduits of the cord simply can't get messages back and forth when collagen blocks the passage of these messages. One worker in my laboratory is trying to characterize spinal cord collagen after injury. Drugs are already available to prevent collagen deposition and allow regeneration. I predict that this line of investigation will also prove to be useful in the clinical recovery of these patients.

B. Pressure Sores: many patients with SCI develop large open wounds below the area of spinal cord injury. We are constantly moving when we sit or lie down because we sense pressure as discomfort and therefore we move. SCI patients have no feeling, cannot move because they are paralyzed and hence develop these huge crater-like tissue defects which debilitate and kill. Sponsored by P.V.A., my laboratory is studying wound healing in SCI patients because we believe that pressure alone cannot account for these terrible wounds. We have devised a small plastic-like tube inserted through the skin which is easily removed after a few days. The contents of the tube are examined for collagen content, types and inflammatory response. Once the specific healing defect which occurs after SCI is defined, we will be able to prevent it and greatly diminish the incidence of these devastating wounds.

C. Clinical Research on Re-Inervation: the clincial state of the art is such that we should be able to perform nerve grafts, extending from normal areas to the areas without functional nerve supply. This will allow us to by-pass the non-functioning spinal cord and to provide sensation (which will alert the patient that tissue damage is occurring) and even restore motor function. Support of such work should not be very expensive and should give clinical results here and now.

D. Psychological Aspects: SCI is emotionally devastating. We must learn to understand and treat better the emotional problems of these patients.

III. VA SCI Centers.— The SCI Center at the McGuire V.A. Hospital is my source of reference.

A. Plastic Surgery: fortunately, Dr. Hunter Jackson of my clinical staff has devoted a major portion of his interest over the past 30 years to the management of wounds in these patients. This one man is adored by patients and staff. Our University Service has added a tremendous clinical clout to the SCI Service because of the many new innovations which have developed in the closure of these challenging clinical wounds. Most of the clinical surgery is now done by my full-time residency and attending staff from the Medical College of Virginia. Financially, it is a bargain for the V.A. The vets get expert care and hospitalization time has been cut down to a minimum. These patients would never receive such quality care without the University affiliation. The old smoldering concept that residents practice on vets just isn't true.

B. Quality of Care: I cannot conceive that any private sector facility could be better than that offered at our VA facility. However, several problems exist:

(1) Nursing Care in Hospital: there appears to be a significant turnover among the "workers" in the system, i.e., at aide, orderly and LPN level. They really become "skilled" at what they do for these patients and yet they leave because of better financial opportunities. They need better financial support.

(2) SCI in Elderly: a population of SCI patients over 60 is rapidly developing because WWI and Korean vets as well as vets who sustain civilian injuries are often in this age group. Moreover, we are much better at keeping these patients alive. Long-term centers for care of those over 60 have been developed in Hampton, Virginia and Boston, Massachusetts. Neither institution has a SCI center. This should be changed to that *all* SCI patients are treated at SCI centers regardless of age.

(3) Attendant Care: we can keep patients *out* of the VA in-patient facilities if good "attendant care" is provided in the home. Good "attendant care" would decrease the number of required admissions for SCI patients and save countless dollars. The V.A. should therefore initiate a program for training "attendants" for home care and send these into the community.

IV. Interrelationships with the private sector.—A. Will the V.A. SCI Centers Have a Greater Role in the Private Sector: SCI management is so good at the McGuire V.A. Hospital and so haphazard in the community that one wonders if the V.A. excellence can't be opened to the private sector. SCI patients scattered in private hospitals can never receive the total comprehensive care offered at the V.A. At least this is true in my area. Should the V.A. centers be open for the lay population to a greater extent?

B. Education of Private Sector: The SCI center at McGuire V.A. has got the care of those patients down to an efficient, health-providing cost-saving science. However, care of these patients in the private sector is haphazard at best save for a few outstanding examples of institutions which render superb care.

(1) Management Courses: The V.A. should teach those rendering home and hospital care in the private sector by establishing training programs. This would cut down on expensive, useless modes of therapy and repeated hospitalizations and surgical interventions. The home visiting nurse programs for these patients are inadequate and could be improved greatly.

V. Summary.—My spinal cord injury research is sponsored by the Paralyzed Veterans' Association. The patients are paying out of their own pockets for research on their own disease. Support is needed through V.A. and N.I.H. grants.

Gentlemen, SCI care at the V.A. has come a long way, thanks to Congressional support. Decisions you make during your tenure in office may allow us to create wonders more spectacular than man walking on the moon.

Consider the impact of the SCI patient who can get up and walk. This can only be made possible by the mandate and support of those in this room.

Respectfully submitted.

I. KELMAN COHEN, M.D.,
Professor of Surgery and Chairman.

STATEMENT OF JOHN F. SOMMER, JR., DEPUTY DIRECTOR, NATIONAL VETERANS AFFAIRS AND REHABILITATION COMMISSION THE AMERICAN LEGION

Mr. Chairman and Members of the Subcommittee: The American Legion appreciates this opportunity to present its views on the Spinal Cord Injury Program of the Veterans Administration.

What we are presenting to the Subcommittee is a series of perceptions of the Spinal Cord Injury Program as we have them through reports of our Field Representatives who regularly make site visits to VA medical care facilities, and through information received from American Legion Service Officers and other members of our organization who are active in support of the patients in the VA health care program.

The Legion recognizes the fact that the Veterans Administration has been a pioneer in the field of providing care and treatment for patients with spinal cord injuries, and that the VA Spinal Cord Injury Service possesses capabilities far surpassing those available in the private sector.

In the highly critical Study of Health Care for American Veterans conducted by the National Academy of Sciences, National Research Council pursuant to section 201(c) of Public Law 93-82, there was only one major criticism of the Spinal Cord Injury Units in VA medical centers. The site visitors found in five of the six SCI centers visited that there was no effort to separate the newly injured patients from those who had been hospitalized for long periods of time. It was felt that such an environment created a sense of hopelessness in the acutely injured patients.

The Veterans Administration, in its response to the NAS Report, stated that the agency was aware of this difficulty and had been working actively to separate the two groups of patients.

The American Legion has more recently become aware of additional problems within the SCI Centers which will be addressed momentarily.

The American Legion is cognizant of the Department of Medicine and Surgery's general policy regarding the treatment of veterans with spinal cord injuries with the Spinal Cord Injury Centers. An important aspect of that policy is the preparation for return of SCI patients to productive community living as early as possible. Consequently, motivation and goal setting involving the patient and the patient's family are initiated promptly, to include vocational counseling, assessment of educational potential, vocational training and assistance in employment placement. SCI patients are to be provided psycho-social assistance in accepting and adapting to the more restricted physical role, and helped to resolve problems involving family, employers and others.

The Annual Report of the Administrator of Veterans Affairs for Fiscal Year 1981, shows that during that year, VA operated nineteen SCI Units, in which it delivered treatment to 6,890 inpatients, and provided care to outpatients with a total of 30,358 visits. The Hospital-Based Home Care program made 5,941 visits to SCI patients.

During the past two years the VA has developed a classification of levels of care: acute, intensive rehabilitation, sustaining care, and long-term care. Each unit has been assigned one or more of these missions according to its capabilities.

There are problems in the SCI System, resulting mostly from limited resources due to inadequate funding.

Site visit reports of American Legion Field Representatives reflect staffing shortages in many of the SCI Centers which are accompanied by morale problems, and in some cases bed closures. We would like to provide the Subcommittee information taken from these reports which reflects the most pressing needs as we perceive them, in the SCI Units.

The most recent visit was completed during the period June 28—July 1, 1982 at the VAMC Bronx, NY. Among the deficiencies in the SCI Unit reflected in our report was a lack of storage or adequate office space. It was noted that support personnel has been deteriorating; morale is poor and burnout is high. The yearly turnover rate is between 20 percent and 25 percent. In May 1982, five staff left because of "traumatic injuries," and four transferred out of the unit. Some of the positions cannot be filled because the staff are still assigned to the SCI Unit. The majority are from Nursing Service.

There are plans to activate 20 additional long-term beds, and they could be readily filled. However, better stabilization of the staff is necessary first.

Hines VAMC, April, 1982—"Discussions with Head Nurses indicate the immediate need to reevaluate staff quotas and increase staffing levels. It was stated that newer injuries cannot be afforded the nursing time needed to meet their physical and psychological needs. Additionally, nurses reported that overall morale within this unit is low and that administrative duties are falling behind. Student nurses

oftentimes act as staff nurses out of desperation. The need for a full-time Orthopedic Physician specifically for SCI was also expressed by nursing personnel.

"The most glaring staffing need within this unit is the lack of Physical Therapists (PT). Reportedly, 5 PTs should be assigned to this unit. Currently, only 1.5 PTs are assigned due to hospital wide vacancies."

Houston VAMC, October 1981—"*Spinal Cord Injury (SCI)*: The 22 beds allocated being treated and support services are good. The noticeable deficiencies had to do with the condition of the open treatment areas. A lack of privacy exists. Plans have been submitted for a new treatment building, however, to date funds have not been released."

While the VA authorizes personnel in SCI Units at a 2 to 1 staff to patient ratio, the medical centers do not always assign this level of staffing to the units. In an attempt to justify this, the number of support service personnel that are required to service the SCI unit are included. This overlooks the glaring fact that the primary care on the ward needs this level of staffing or better. These patients, especially the quadraplegics, are so helpless that it requires several people to move them and care for them.

These are but a few examples. However, they are representative, by and large, of all the most recent reports on SCI Centers by our Field Representatives. In every case, the major problems reported stem from shortages in personnel, particularly nurses and physical therapists; and space.

This Subcommittee is to be commended for recognizing the critical nationwide shortage of nurses in the VA medical care system, and holding hearings on the issue on March 17, 1982.

The American Legion believes it urgent that Congress address this situation by providing VA with substantially greater capability in offering fringe benefits and other inducements to attract nurses.

It is also obvious that the shortage of physical therapists must be addressed, as this is a major problem within the SCI operation. Approximately 17 percent of all physical therapists positions are vacant. As with the nurses, it is difficult at best for VA to compete with the hospitals in the private sector, which enjoy a freedom from the limitations and restrictions that constrain the Veterans Administration's recruitment and retention activities.

As for space and bed shortages, we have learned that the Department of Medicine and Surgery, we have learned that the Department of Medicine and Surgery is actively considering the implementation of smaller (25–30 bed) SCI Units in areas such as Albuquerque, Salt Lake City, Denver, and near other metrorpolitan areas where there is a substantial population of veterans with spinal cord injuries, for the purpose of providing immediate local care, and eliminating the need for SCI veterans to be hospitalized hundreds of miles from their families.

In its Report for fiscal year 1981, VA states that a major demographic survey of the SCI veteran population is presently being conducted to identify their geographic and other characteristics. This will permit a more accurate data base on which to plan the allocation of services.

To The American Legion's thinking, the development of strategically placed smaller units would maximize spinal cord injury treatment by providing immediate local care where the greatest needs exist, relieving currently overburdened SCI units, and accomplishing a reduction in the size of larger underutilized units so that the underused beds may revert to treatment areas wherein there is a greater level of demand for hospital beds.

Mr. Chairman, and Members of the Subcommittee, the successes of the Veterans Administration in increasing the life expectancy of spinal cord injury patients, combined with the high incidence of these injuries patients, combined with the high incidence of these injuries annually, is placing increasing demands upon the VA's SCI Service. The American Legion urges that you give serious consideration to the resources necessary to enable the VA to continue its provision of high quality spinal cord injury care as the demand for such care increases within the VA system.

We thank the Subcommittee for receiving our views.

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